# Evaluating adapted physical activity-based rehabilitation in people with chronic disabilities

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“I believe that our potential is unlimited because we are part of the eternal universe, that incomprehensible divinity which through the mystery of faith liberates our thought and abilities. But I also believe that our shortcomings are unlimited because we are human. Herein lies our greatness and our challenge.”

- Erling Stordahl, founder Beitostølen Health Sports Center

“Vårt helsesportsenter skal fylle den store oppgaven – å bringe helse, hjelp og pågangsmot til grupper i vårt samfunn som trenger det mer enn andre i sin bestrebelse for å leve et rikt og skapende liv”

- Erling Stordahl, founder Beitostølen Health Sports Center

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This PhD started as a project at the *University of Oslo's Medical Student Research Program* in 2014. My intentions were to get to know the field of research and to explore the unknown world of rehabilitation medicine. I have always been drawn to places like BHC where one can escape everyday life and concentrate on concrete tasks for a limited time period. It is also a place where people can meet others who may face challenges comparable to their own. These centers and institutions attract workers who are really passionate about what they do, going great lengths to offer the best care possible. The clients and workers at BHC have taught me so much about rehabilitation medicine, living with a disability and about seeing opportunities, the latter both at work and in everyday life. Thank you for great times!

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# TABLE OF CONTENTS

# ABSTRACT

*Purpose:* To evaluate short- and long-term outcome of rehabilitation based on adapted physical activity (APA) on mental and physical functioning for people with chronic, mainly physical disabilities. In addition, to explore the goal-setting process in terms of content, achievement and influence on outcome.

*Research design:* A randomized double-blind waiting list-controlled study followed by a 12-month prospective follow-up-study.

*Methods:* The study included adults (18-73 years) with chronic disabilities who were admitted to a four-week APA-based rehabilitation stay at Beitostølen Healthsports Center. In the double-blind randomized controlled trial (Clinical Trial Gov number NCT01788397), subjects were randomized to intervention or control (waiting list). The waiting list-group received delayed intervention and subjects from both groups were followed for 12 months. The subjects completed written questionnaires eight and four weeks before rehabilitation, at admission and discharge, and again four weeks and 12 months after discharge. Mental and physical functioning was measured by the *Physical and Mental Component Summaries* (PCS and MCS) of The *Medical Outcomes Study 12-item Short Form Health Survey* (SF-12). Possible predictors included pain, fatigue, motivation, self-efficacy and goal achievement. Subjects set individual goals in the study admission questionnaire. Negotiated goals were part of the observed intervention, and were elaborated in a meeting with the rehabilitation team on the second day of the intervention. The goals were linked to categories in *The International Classification of Functioning, Disability and Health* (ICF) to ensure comparability. Goal achievement was measured at discharge.

*Results:* Compared to waiting list, the intervention significantly improved the subjects' physical and mental functioning four weeks after rehabilitation ($p=0.001$ and $p=0.02$, respectively). The SF-12 PCS and MCS improved with 3.76 and 3.79 points, respectively. Improvements were associated with increased self-efficacy for social and recreational activities during rehabilitation. Trajectories revealed that the detected improvement in physical and mental functioning sustained after one year ($p<0.001$). Mean improvement in SF-12 PCS and MCS from baseline to one year was 1.99 and 2.88 points. Long-term improvement was associated with low self-efficacy for managing chronic disease and high levels of fatigue at baseline, non-nervous system diseases and goal achievement. Rehabilitation goals set by the individuals were most frequently linked to the ICF-component

*Body Functions*. After goal negotiation with the rehabilitation team, the portion of goal codes that could be linked to the ICF increased by 7%.
*Conclusion*: Individuals with chronic disabilities participating in an APA- and goal-setting-based intervention improved their physical and mental functioning both at short and long-term follow up. The improvement seemed to be particularly positive for subjects with fatigue and low self-efficacy, and for those who experienced goal achievement. Health professional's involvement in goal-setting seemed to benefit more specific goals and a higher relative frequency of goals directed towards activities and participation.

**Keywords:** Adapted physical activity, disability, rehabilitation, participation, functioning, goal-setting, International Classification of Functioning, Disability and Health

# ABBREVIATIONS

| | |
|---|---|
| APA | Adapted physical activity |
| BHC | Beitostølen Healthsports Center |
| BREQ-2 | The 19-item Behavioral Regulation in Exercise Questionnaire |
| CAPE | The Children's Assessment of Participation and Enjoyment |
| COPM | The Canadian Occupational Performance Measure |
| GAS | Goal attainment scaling |
| ICF | The International Classification of Functioning, Disability and Health |
| MCS | Mental Component Summary |
| MCID | Minimal clinical important difference |
| MLM | Multilevel modeling |
| PCS | Physical Component Summary |
| SD | Standard deviation |
| SF-12 | The Medical Outcomes Study 12-item Short Form Health Survey |
| SPSS | Statistical Package for the Social Sciences |
| VAS | Visual Analog Scale |
| WHO | World Health Organization |

# INCLUDED PAPERS

Paper I

***Does adapted physical activity-based rehabilitation improve mental and physical functioning? A randomized trial***

Cecilie Røe, Line Preede, Håkon Dalen, Erik Bautz-Holter, Astrid Nyquist, Leiv Sandvik, Martin Saebu

*European Journal of Physical and Rehabilitation Medicine 2018 June;54:419-27 (1).*

Paper II

***One-year trajectories of mental and physical functioning during and after rehabilitation among individuals with disabilities***

Line Preede, Martin Saebu, Paul B. Perrin, Astrid Nyquist, Håkon Dalen, Erik Bautz-Holter, Cecilie Røe

*Health and Quality of Life Outcomes 2015 Aug 28;13:135 (2)*

Paper III

***Individual rehabilitation goals; what is the content of the goals and do health professionals capture this content?***

Line Preede, Helene L Søberg, Håkon Dalen, Astrid Nyquist, Reidun Jahnsen, Martin Saebu, Erik Bautz-Holter, Cecilie Røe

*Patient Preference and Adherence (submitted)*

# INTRODUCTION

This thesis aims to gain knowledge of the effects of adapted physical activity-based rehabilitation for people with chronic, mainly physical disabilities. It seeks insight into goal setting processes occurring as part of the rehabilitation and evaluates short- and long-term outcome of rehabilitation on physical and mental functioning.

The setting for the thesis is Beitostølen Healthsports Center (BHC), a pioneer rehabilitation institution in Norway. The institution provides services to people with disabilities at all ages with the guiding principle of activity and participation and focus on opportunities instead of constraints. Already in 1978 Gregg Reed wrote about BHC in an editorial in the journal "The Physician and Sportsmedicine" with the heading "Beitostølen: Shangri-La for the Handicapped" (3). The editorial highlights three important aspects; at BHC sports are considered medical care; emphasis is put on what you can do instead of limitations; the goal is to give people self-confidence, self-respect, and a better adjustment to the world outside (3). More than 40 years later, these values are still important at BHC.

Disability means living with the consequence of your impairment and trying to minimize impact on independency, functioning and participation in the community. Functioning is The World Health Organization's (WHO) third health indicator after morbidity and mortality (4). The gap between experienced and desired levels of functioning can be reduced by adaptation of the environment as well as by increasing functioning through rehabilitation (5).

## Disability

According to The World Health Organization (WHO) World Report on Disability, more than a billion people are estimated to live with a disability, or about 15% of the world's population (based on 2010 global population estimates) (6). The *World Health Survey* states that around 785 million (15.6%) persons from the age of 15 years, live with a disability and that 110 million people (2.2%) have very significant difficulties in functioning (6). Statistics Norway (Statistisk Sentralbyrå) reports that in 2019 17.4 % of the Norwegian population aged 15-66 had a disability (7).

Disability is defined by WHO as an umbrella term covering impairments, activity limitations, and participation restrictions. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (6). To some extent, WHO embraces both the medical perspectives for understanding disability, emphasizing the importance of the underlying disorders and body impairments (8), and the social perspectives focusing on the societal and environmental factors (9). The social model, has a clear distinction between impairment and disability where the latter is created by social exclusion from the society and not by the impairment (10). Several models have been developed in order to embrace the complexity of disability (11-14), many of them highlight the importance of the environment in creating disability to a greater extent than WHO.

The Norwegian government states that disability is experienced when there is a disparity between the individual's assumptions and the demands stated by the environment and the community when it comes to maintaining a function in areas that are crucial to establish and keep independence and a social presence (15). This underlines how important the influence of the context on the person is when creating disability.

*Health problems and environmental challenges*

The specific problems vary according to the nature of the impairment and comprise problems within the cognitive, emotional and physical domains (16).

Pain is one of the most frequent problems associated with disability particularly in musculoskeletal and neurological conditions. It is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (17, 18). Pain may contribute to decline in functional level, limitation in physical activity and also impact quality of life (19-22). Fatigue is another frequent symptom associated with disability (23) and can be defined as *a subjective lack of physical and mental energy that interferes with usual activity* (24). Physical activity is reported by people with disabilities as one of their main strategies to manage fatigue, but also as a contributor to fatigue (25). Activities of daily living might require most of their available capacity, creating a sense of fatigue that will influence the engagement in physical activity (26). Reduced physical activity levels because of pain and fatigue, but also leading to pain and fatigue,

initiates a vicious circle. Furthermore, self-efficacy, identifying with being a physically active person and motivation towards physical activity, are affected when living with a disability (27-29). These factors are shown to be relevant for exercise behavior and crucial for activity (30-33), irrespective of origin of disability or surroundings. Self-efficacy is defined by Bandura as *people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances. It is concerned not with the skills one has but with judgments of what one can do with whatever skills one possesses* (34). Those with high self-efficacy expect to realize favorable outcomes and will not give up in the face of difficulties. Those with low self-efficacy expect their efforts to bring poor outcomes and they easily give up trying (35).

In addition, the way the environment is designed is both a consequence of disability and a contributor to disability. Examples are lack of universal design, difficulties with moving in and out of transport and not being self-reliant in activities of daily living. These problems have one thing in common; they impact the possibility of the person with disability to be active and participating in everyday life (36).

## The International Classification of Functioning, Disability and Health

Along with increasing biopsychosocial focus in disability and rehabilitation, the work of developing a framework and classification that could capture these dimensions was started (37). Based on this work the *The International Classification of Functioning, Disability and Health (ICF*) was launched in 2001 (11, 38). The classification provides a standard vocabulary and a list of categories to describe aspects that might influence functioning, disability and health (Figure 1). The framework allows health personnel to describe barriers arising when trying to participate, being active and improving body function disrespectable of the underlying health condition (39). Contextual factors are included and divided into environmental and personal factors. As a result, not only the person, but also the way the person interacts with the community, is described and can be analyzed accordingly.

The ICF comprises four dimensions: *Body Functions* (b), *Body Structures* (s), *Activities and Participation* (d) and *Environmental Factors* (e) (11). Personal factors are included in the ICF, but are not classified. The classification gives a range of alphanumeric codes; the first letter describes the dimension; the first digit describes which domain is covered; the two

following digits describe specific aspects of functions included in the domain; fourth and sometimes fifth digits provide more details (40). According to the ICF, the term "Functioning" encompasses the dimensions Body Functions, Body Structures and Activities and Participation and is viewed in relation to the health condition as well as personal and environmental factors. "Disability" is complementary to functioning and encompasses impairments in body functions and structures, limitations in activities, and restrictions in participation (41)

The framework as well as the classification of the ICF is extensively used in research and to guide the needed actions in rehabilitation (42). It is also an underlying premise for the present thesis.

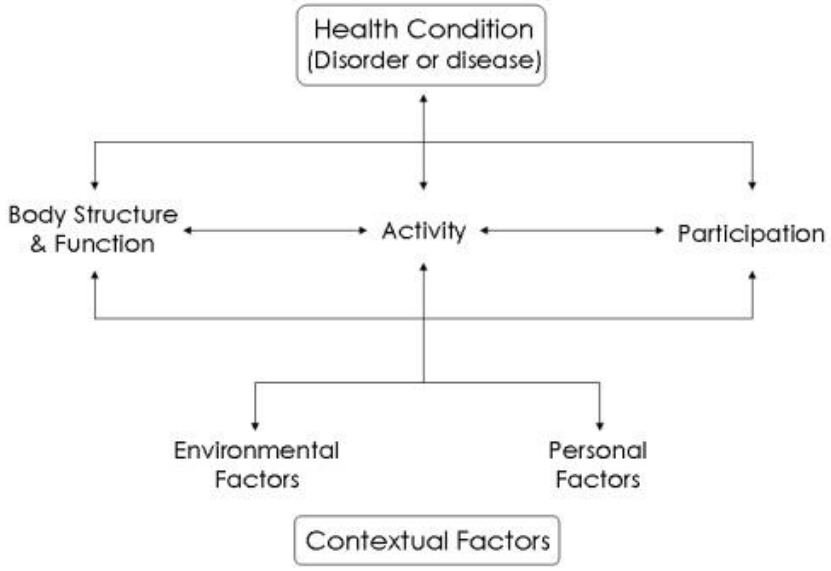



**Figure 1**: The ICF model (2001) Functioning, disability and health is illustrated in this model as a dynamic interaction between the health condition and contextual factors that is carried out through changes in body structure and function, activity and participation (43).

## Rehabilitation

A variety of definitions for rehabilitation exits. The majority focus on achieving optimal functioning in interaction with the environment. As defined by *United Nations Convention on the Rights of Persons with Disabilities* (44), habilitation and rehabilitation *enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life*. This definition focuses on the aim of the rehabilitation. The new Norwegian definition (45),

focuses both on the aim and the processes: *Habilitation and rehabilitation must be based on the life situation and goals of the individual patient and user. Habilitation and rehabilitation are targeted collaborative processes in various arenas between patient, user, relatives and service providers. The processes are characterized by coordinated, coherent and knowledge-based measures. The purpose is that the individual patient and user, who have or are at risk of being restricted in their physical, mental, cognitive or social functioning, should be given the opportunity to achieve the best possible functioning, coping ability, independence and participation in education and working life, socially and in the community*.

In accordance with the biopsychosocial model of disability, the field of rehabilitation has developed to imply integrated multidisciplinary interventions covering medical, functional and environmental aspects. The modern paradigm of rehabilitation is that early rehabilitation interventions should be part of the acute inpatient hospital treatment carried out alongside surgical and medical treatment (46-48). Post-acute and chronic phase rehabilitations follow the acute treatment and seeks to regain or restore functioning in order to enable meaningful participation (46, 49). In the Scandinavian countries including Norway, post-acute and chronic phase rehabilitation is funded by the government and carried out in municipalities, hospitals and specialized institutions.

*Content of rehabilitation interventions*

Rehabilitation services may be generic or diagnosis specific and the content varies across the level and nature of the impairments and disabilities. Typically, rehabilitation interventions comprise several components and are examples of complex interventions (50). Thus, describing the exact content and processes involved in these interventions has been difficult for rehabilitation practitioners and has often been described as a black box (51, 52). Keith stated the following over 20 years ago: "Lack of identification of the components of treatment has meant we do not know which procedures in rehabilitation are essential to produce improvement, a necessary ingredient in efficiently instituting alternative treatment methods" (53). Researchers have tried to look into the black box and find out how the ingredients, through a mechanism of action, lead to improvements in aspects of functioning they aim to improve. They pinpoint the need for knowledge on theory of rehabilitation in order to improve knowledge of what really happens in the black box (54-56).

Two broad classes of theories, *treatment theory* and *enablement theory*, constitute a basis for many of the rehabilitation interventions used today (57). *Treatment theories* are theories about how to effect change in clinical targets. They describe how particular active ingredients directly alter specific aspects of functioning (58). For example, how doing squats will improve you lower body muscle strength. The theory distinguishes between *active ingredients* leading to a change in treatment target, and *inactive ingredients* not leading to change. *Enablement theories* are theories about how changes in a proximal clinical target will influence distal clinical aims (57). They hypothesize how changes in various levels of functioning are interrelated with one another and translate into changes in other aspects (58). For example, how improving your lower body muscle strength will make it easier to walk, which again will make it easier to work and participate in everyday life. *Enablement theories* provide no insight as to how the initial functional change is produced. Thus, the tools for change must be supplied by treatment theories, but the nature of the resultant distal clinical impact is predicted by enablement theories. The two theories have to be combined if we want our treatments to be effective and have clinically useful functional impact (57).

When it comes to treatment theory, researchers have introduced a *tripartite structure* describing how clinician-provided *ingredients*, through a *mechanism of action* (how the treatment is expected to work), bring about functional changes in a clinical *target* in a causal chain (59). It can be reversed into a chain of clinical reasoning happening when the clinician determines the aspects of functioning that need changing, decides on a mechanism of action to bring about the change and then selects the ingredients expected to engage that mechanism. If we also include what happens in the patient-clinician interactions and other aspects of the health care system affecting the patients (58), we are including the patient's needs into the clinical reasoning of the tripartite structure. The desired result of this structure is to develop individually tailored rehabilitation programs based on patient-clinician negotiated goals, containing active ingredients to bring about change in functioning or adaptation.

The ICF-model is extensively used when tailoring rehabilitation interventions, both to ensure a biopsychosocial perspective when addressing clinical targets, but also when selecting active ingredients covering the different dimensions illustrated in the model. One of the more general active ingredients offered in improving function, activity and participation, is physical activity. Physical activity is defined as "any bodily movement produced by skeletal muscles that results in energy expenditure" (60). It differs from exercise which is defined as "a subset

of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical fitness" (60). It is often difficult to differentiate between physical activity and exercise, and to some extent all physical activity may also improve or maintain physical fitness even if it is not the intended reason for the activity. Physical activity and exercise is shown to improve both physical and mental health (61-64). Sedentary behavior is defined as "any waking behavior characterized by an energy expenditure ≤1.5 metabolic equivalents while in a sitting, reclining or lying posture" (65). Sedentary behavior is linked to a series of lifestyle diseases like metabolic syndrome, type 2 diabetes, obesity, and cardiovascular diseases, underlining the importance of being physically active (66, 67). Even small amounts of physical activity consistent with minimal physical activity guidelines, have health benefits (61). Physical activity is even more important for people with disabilities than for people without disabilities (68). People with disabilities have higher rates of lifestyle diseases and other secondary conditions that physical activity can prevent (69-71). Physical activity has also shown both emotional, cognitive and social benefits (72, 73). Even though the importance of physical activity is stressed, literature shows that individuals with chronic disability have a decreased physical activity level, not meeting the basic recommendations (74). In fact, they are only half as active as able-bodied (75). One explanation is that activities of daily living might require most of the available capacity (26), influencing the engagement in exercise and sports. Another explanation can be that the degree of impairment and the medical problem interferes with the possibility for participation in sports and leisure activities (76, 77). In either way, not participating in physical activity leads to further deconditioning and a greater threshold for participation. This makes physical activity as an active ingredient important both in order to improve functioning and capacity and to learn to adapt the activities in such a way that you can participate.

According to the ICF, functioning, activity and participation are also dependent on contextual factors. In the chronic phases of disability, medical treatment may be less pertinent, whereas the contextual factors have larger impact on the person's life. When designing chronic phase rehabilitation interventions, active ingredients should target the environmental and personal factors in addition to targeting functional impairments. A cognitive or more behavioral focus has been included over the last decades, recognizing the importance of the psychological factors implicit in chronic conditions (78). Psychological factors or the personal, psychological and environmental interactions have been considered targeting for example the fear avoidance beliefs for physical activity or work (79). Self-efficacy is a related

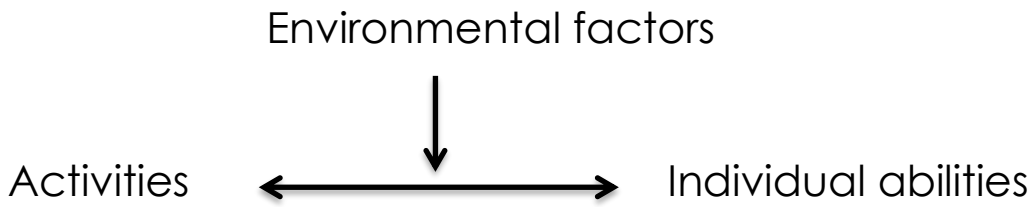
phenomenon focusing more on the beliefs in own abilities than the fear and studied in a wider specter of patient populations (80, 81). Enhancing the person's thoughts regarding own physical or mental capacity, but giving them the opportunity to experience that they actually are able to reach their goals, are important elements in such interventions. In the ICF the construct of capacity and performance is highlighted (11). The individual may need assistive devices, technology or environmental adaptations in order to perform at the level of their capacity. These elements have traditionally been less focused in health related rehabilitation interventions (82), but is an important part of the rehabilitation program studied in this thesis.

*Healthsports and adapted physical activity*

As a result of the visions of the founder of BHC, the term *healthsports* was created in Norway in 1958 (83). In the beginning the term covered a wider spectrum and included physical activity for persons with disability, recreational activity for the community in general and ergonomic exercises in work environments. Today healthsports is defined as *physical activities designed to suit the individual and improve physical abilities where the goal is to improve mental, physical and spiritual wellbeing* (83). Healthsports are used in both preventive health care and in rehabilitation of people with chronic or temporary disabilities. One can say the term is a national variant of the international term *adapted physical activity* (APA).

APA refers to physical activities adapted to the specific needs of each individual with a disability (84). The interventions are based on general principles for rehabilitation including goal setting and aiming to improve self-efficacy and functioning. In addition, APA-based rehabilitations include the active ingredient of adaptation of different activities to fit each individual's needs in the rehabilitation setting. The main focus of APA is on possibilities for participation in the environment and not on limitations for activity (Figure 2). Instead of adapting the person to the activity, the activity is adapted to the person. This may include adapting assistive devices for sports and leisure, and also provide suitable environments. It may also include adaptation of attitude towards sports and leisure activities in disability. The focus of APA is not on diagnoses, with the result that most APA-based rehabilitations are catered for patients with a mixed diagnostic background. BHC has been in the forefront on rehabilitation interventions based on APA for decades and the approach is the focus of this thesis.

Figure 2. Theory of APA. There is a dynamic interaction between activities and a person's individual abilities, this interaction is affected by environmental factors.




*Goal-setting in rehabilitation*

Active ingredients should be based on the individual needs and goals, conducted in close collaboration between the health professionals and the patient (85, 86). This makes goal-setting a key element in the rehabilitation process (87). Goal-setting is conducted in order to improve patient outcomes, but also to enhance patient autonomy, evaluate outcome and to respond to contractual, legislative or professional requirements (88). Improving patient outcome is associated with enhancing patient motivation, specificity of training, teamwork and secondary therapeutic effects, such as improving self-awareness (88, 89).

The theoretical understanding of goal setting in rehabilitation originates from psychology research summarized and led by Locke and Latham (90). Studies showed that specific, high (hard) goals lead to a higher level of task performance than easy, abstract or vague goals do. Performance leveled off only when the limits of ability where reached or when commitment to a highly difficult goal lapsed (90). Vague "do-your-best"-goals allows for a wide range of acceptable performance levels resulting in persons asked to do their best not doing their best, but still reaching their goal (90). As long as the person is committed to the goal, has the abilities to attain it and does not have conflicting goals, there is a positive, linear relationship between goal difficulty and task performance (91). Locke and Latham also found that the key moderators of goal setting are feedback, commitment, task complexity and situational constraints. Commitments are enhanced by self-efficacy and viewing the goal as important. When task complexity increases, goal effects are dependent on the ability to discover appropriate task strategies (91). The concept of self-efficacy is important in goal-setting theory in several ways. When goals are self-set, people with high self-efficacy set higher goals than people with lower self-efficacy do. People with high self-efficacy are more

committed to assigned goals, find and use better task strategies to attain the goals, and respond more positively to negative feedback (90).

Derek Wade (92) defines a goal as *a future state that is desired and/or expected. The state might refer to relative changes or to an absolute achievement. It might refer to matters affecting the patient, the patient's environment, the family or any other party*. Goal setting or goal planning is defined as *the process of agreeing on goals, this agreement usually being between the patient and all other interested parties* (92). The use of goal setting provides benefits for both the team and the individual (87). Playford et al. address that goals should be patient-centered, specific, ambitious and time limited (87). The goals do not necessarily need to be achievable, but they must reflect ambitions for the person involved. A goal also involves a change or at least maintenance of the current state. Goals are both intended consequences of actions during an intervention, like getting stronger, and intended results of the intervention, like being self-reliant (93). Goal planning is associated with more behavioral change than when there is no setting of goals and this behavioral change is more likely if the goal planning is supported by specific interventions intended to facilitate the behavioral change (86, 92).

A well-known problem with goal setting is the lack of a common vocabulary. In order to carry out research on goal setting, a consistent road to comparison is necessary. The ICF has been used to structure the goals and facilitate the goal setting process when it comes to comparability and reproducibility. Mapping goals to the ICF can help us identify specific targets for interventions and establish a common language within the multidisciplinary team and between researchers (94, 95). During the past ten years a lot of guidance has been given in terms of translating the individually verbalized goals into the ICF, rules to linking have been given and updated by Cieza et al. (38, 96).

When rehabilitation interventions are not experienced as person-centered and individualized, patients experience dissatisfaction (97). Health professional's ability to capture patients concerns and perspectives is essential for the patients in reaching their personally valuable goals (97). In accordance, goals and outcomes considered important by the health professional should be in accordance with those of the patients. Advantages of patient involvement in goal-setting are increased patient motivation, patient satisfaction, better goal attainment and better outcome (98-101).

Previous research on goal setting shows a discrepancy between patients and health providers reported goals (102, 103). Where health providers tend to set goals focusing on impairment, patients tend to have a more participation-centered focus (102). Impairment goals might be common amongst professionals because these goals are easy to measure and evaluate, allowing patients to see obvious changes in their presentation, increasing motivation to achieve goals (104, 105). Rice et.al. (106) found that when evaluating goals, patients were significantly more satisfied with their impairment-based goals than activity- and participation-based goals, concluding that they may represent goals more realistically accomplished during rehabilitation (106). Still, when patients are involved in goal-setting, they tend to set goals regarding activities and participation (102, 107, 108).

Researchers have stressed the need for more research on goal-setting in rehabilitation for decades (92). Wade proposed already in 1998 that setting goals may improve the long-term effectiveness of interventions (92). Research on effects of goal setting is complex especially when it comes to outcome. There is still conflicting evidence supporting goal setting as an effective predictor for improved outcome (109, 110). Goal achievement measures including Goal Attainment Scaling (GAS), has been applied as useful in evaluation outcome of a variety of rehabilitation interventions (110, 111). There is also a known association between goal achievement and improvement of functioning (112, 113). Research regarding goal achievement in populations with chronic disabilities attending rehabilitation is scarce. The same can be said for the use of standardized outcome measures in the evaluation of goal-setting procedures and goal achievement. In spite of several years with research focusing on participation and goal-setting in rehabilitation, very few studies have observed real-life clinical practice goal-setting processes.

## Outcome of APA-based rehabilitation

When evaluating outcome of APA-based rehabilitation we want to evaluate if the individually tailored active ingredients and goals that APA concerns, bring about the desired change in activity and participation. A number of outcome measurements within the field of activity and participation are developed to cover the problems of specific diagnostic groups. In APA-based rehabilitation the patients have a mixed diagnostic background and the desired outcome may be highly individual. The challenge when evaluating patient specific outcomes is that they cannot be scaled equally. This raises issues when we want to investigate changes on a

group level. Hence, there is a paucity of validated generic outcome measures regarding activity and participation, even though the literature stresses the relevance of participation as an outcome (114-118).

In the ICF, activity is defined as *the execution of a task or an action by an individual*, while participation is defined as *involvement in a life situation* (11). Measuring activity regards measuring the execution of the task or action. It can be done by registration of the activity through observation or instruments or by self-reported measures. Participation on the other hand, is a challenging construct to measure (118), partly because perceived participation is not dependent of the activity, it is the subjective feeling of participation that matters (117). It is also important to differentiate between participation defined as attendance in activities and as involvement in activities (119). Christine Imms et al. have developed a model called *the family of participation-related constructs,* addressing participation as defined by the ICF with these elements (115, 120). Attendance is defined as *being there* and measured as frequency of attending and/or the range or diversity of activities. Involvement is defined as *the experience of participation while attending* including elements of engagement, motivation, persistence, social connection, and level of affect. Attendance is easily measured while involvement is a more complex process (115). The model presents three intrinsic factors of participation; activity competence defined *as the ability to execute the activity being undertaken according to an expected standard*; sense-of-self defined as a *personal perception related to one's confidence, satisfaction, self-esteem, and self-determination*; and preferences defined as *the interests or activities that hold meaning or are valued.* The model positions participation as both an entry point and primary outcome of intervention, stating that participation is both a means and an end (115), meaning that even though participation is the end point, to be participating is one of the key points in creating participation, it is an active ingredient.

Evidence exists that interventions focusing on the level of body function has little direct effect on participation, suggesting that a more direct approach to changing participation is more likely to have an effect on participation as an outcome (121). Participation research suggests that we should view participation as an active ingredient in the rehabilitation intervention, an entry point for changes at the body functions/structures and activity level, and not a downstream effect of rehabilitation focusing on body function and activity levels (115). In the present thesis participation is included as an active ingredient in the rehabilitation intervention studied, but participation is also a favorable outcome of the intervention. The outcome

measure used is not a participation measure, mainly because of the previously mentioned paucity of validated generic outcome measures regarding participation.

Participation and health related quality of life can be linked, suggesting restricted participation is likely to influence health related quality of life (HRQoL) (122, 123). After the present study was conducted, Van de Velde et al. developed an instrument for measuring perceived participation – The Ghent Participation scale (124). When evaluating the scale, they used a HRQoL-measure (SF-36) almost identical to the one used in this thesis to assess whether the Ghent Participation Scale distinguishes participation from HRQoL (117). They found higher correlations between the two measurements than expected, suggesting participation and HRQoL are more related constructs than the research group had assumed (117). Still it is important to bear in mind that HRQoL does not cover the whole aspect of participation. Generic measurements of HRQoL have been developed and thoroughly validated (125-127). These instruments measure functioning in general and not only participation. They are often divided into measurements of physical and mental functioning (128).

Several studies are investigating effects of physical activity on quality of life (129-132), but there is a lack of research investigating effects of APA on quality of life, especially regarding people with chronic disabilities. Cugusi et al. found positive short-term effects of an APA-program on quality of life in a small sample with Parkinson's disease (132). Taricco et al. had similar results on physical functioning following an APA-program for patients in the post-acute phase after stroke (133). Studies investigating long-term effects are lacking.

## The importance of the present study

Given the gap of knowledge regarding APA-based rehabilitations for people in a chronic phase of their disability, this thesis seeks to evaluate both the short- and long-term effects of such an intervention on self-reported mental and physical functioning. The thesis also looks into the goal-setting process carried out at the rehabilitation institution, as an attempt to contribute to the gap of knowledge on what is really going on in the black box of rehabilitation, especially when it comes to aspects leading to improved outcome.

# AIMS

- to evaluate the short- and long-term effects of adapted physical activity-based rehabilitation on mental and physical functioning for subjects with chronic disabilities (Paper I and II).
- to determine whether demographic factors, reason for disability, pain, fatigue, self-efficacy and goal achievement influence outcome on functioning (Paper I, II and III)
- to compare individual goals set by the subjects and negotiated goals set in collaboration with the rehabilitation team regarding content and health professionals' ability to capture the individual goals (Paper III)

# MATERIALS AND METHODS

## Setting of the intervention

The setting of the study is Beitostølen Healthsports Center (BHC) which is a rehabilitation institution situated in a small village in the mountains of Norway. BHC was opened Nov 7th, 1970. The institution was to a great extent founded upon ideas and personal experiences of the blind visionary, Erling Stordahl (1923-1994). The center caters rehabilitation to 700 participants every year, both children and adults, and is recognized as an official part of the national specialist health care system in physical medicine and rehabilitation. Possible participants for rehabilitation have to be referred from their general physician or from a physician at their hospital to be enrolled in rehabilitation, which is fully funded by the government. This also includes guides, helpers or parents that are needed for successful participation in the programs. To be enrolled at a rehabilitation stay one need to have a chronic disability that affects functioning. The center does not cater acute and post-acute rehabilitation, participants are in a stable chronic stage of their disease and need rehabilitation to maintain functioning or maximize abilities for improvement.

The objective of the center is, by means of physical, social and cultural activities, to help persons with mainly physical disabilities to achieve optimal functional independence and ability to be active and participate in daily life (134). The focus of the institution is to provide a wide spectrum of activities, in spite of a disability, more than because of a disability. Activities offered are to some extent reflecting the Norwegian activity culture, with great emphasis on outdoor activities. The range of activities that the rehabilitation center offers includes swimming, cross-country skiing, alpine skiing, horseback-riding, aerobics, kayaking and other activities, which allows each individual to determine the activities best suited to him or her. An important part of the rehabilitation process is for the participants to gain knowledge of activities that are adaptable in their local environment and everyday life. The stay at BHC is part of a long-term rehabilitation chain that continues after the participants return home. This is reflected in the overall goal of the rehabilitation at BHC, which is to create a basis for increased activity and participation in the local environment.

The focus of the rehabilitation is not on diagnoses and there are no diagnosis specific restrictions for referral. Diagnoses are used to map restrictions and abilities for activity in the start of the rehabilitation stay. From that point, the focus is on abilities with the specific

disability and creating possibilities for increased activity, including improvement of physical fitness and adaptation of activities.

The adult group attends a four-week stay with two to five hours of physical activity each day. Individual schedules are made together with a multidisciplinary team after goal setting. The facility is an interdisciplinary work environment with physicians, nurses, physiotherapists, APA-instructors, occupational therapists, riding instructors, teachers and social workers. A wide range of services is offered including technical aids, school for children and adolescents, social activities and individual instruction.

BHC has three main functions. The first is delivery of adapted physical activities to people with mainly physical disabilities, combined with medical, pedagogical and social guidance. The second encompasses cross professional research and development done by staff in cooperation with external scientific professionals. The purpose is to document existing experiences and develop new knowledge in the field of rehabilitation where APA is used to achieve personal rehabilitation goals. The third is to carry out courses and educational programs for APA-students and health service personnel at all educational levels. The center receives Norwegian as well as foreign students for practice at the center.

Goal-setting is an essential part of the rehabilitation at BHC, providing a basis for individualized treatments through a structured goal planning process. The health professionals at BHC are familiar with the ICF, and goal-setting and schedule planning is carried out using the ICF framework. The subject is an active participant in the rehabilitation process, and the activity of the rehabilitation team considers the preferences of the subject. Most of the activities are arranged in groups. The group setting is considered important, encouraging participants to work together, give feedback to each other and exchange activity experiences. During their stay, the participants' schedules are regularly assessed and adjusted when necessary.

## Design

The study design was a randomized double-blinded waiting list-controlled study where the control group received delayed intervention. After intervention, subjects from both groups were followed for 12 months in a cohort. The study was approved 27th of December 2008 by

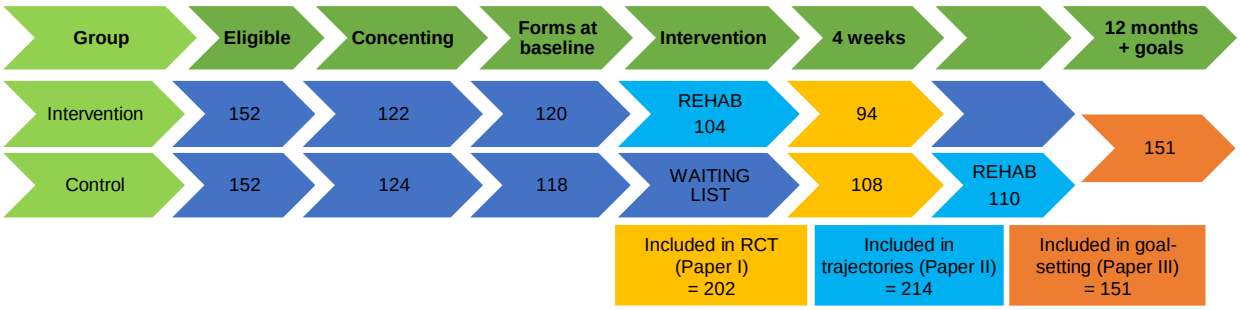
the Regional Medical Committee for Research Ethics in Norway (S-08837c 2008/21144) and registered with ClinicalTrials.gov (number NCT01788397).

## Subjects and data collection

Subjects with chronic disabilities as defined by WHO, aged 18 to 73 years (men and women) and admitted to a four-week rehabilitation stay at BHC were assessed for eligibility. Written invitations with information about the study were sent to the eligible participants. Those who accepted the invitation provided written informed consent and were included. From the subjects admitted to rehabilitation, 321 were assessed for eligibility and 304 were eligible after exclusion. The exclusion criteria were insufficient knowledge of Norwegian to fill out the questionnaires and severe cognitive disorders. All subjects were examined by a physician upon admission to the rehabilitation center and by health professionals according to the subject's specific needs. A team was organized for each subject. On the second day, the team and the subject developed a detailed, goal-oriented plan for the rehabilitation.

Data collection occurred between September 2010 and December 2012. The subjects received written questionnaires eight (baseline) and four weeks before rehabilitation, at admission to and discharge from rehabilitation and again at four weeks and 12 months after discharge (follow-up). To collect data for the RCT, subjects randomized to the waiting list control group, received the two first forms as control group before they were admitted to rehabilitation (Figure 3).

**Figure 3:** Flow-chart of the inclusion in Papers I-III.




The 304 eligible subjects were randomized and subsequently 246 subjects consented to participation (Figure 3). Eight of the 246 consenting subjects did not return the baseline

forms. Additionally, 36 subjects did not attend intervention or respond to the four-week follow up, which resulted in 202 subjects with complete outcome data for the RCT (Figure 3). No statistically significant differences in baseline characteristics were found between the intervention and control group ($p>0.05$) (Table 1). When the control group had undergone rehabilitation, 32 of the 246 consenting subjects had dropped out before or during the intervention. This resulted in 214 subjects who completed rehabilitation and were included in the trajectory analyses for long-term outcome (Figure 3). Of the 214 subjects, 61 did not complete one or more of the 6 questionnaires. They were still included in the trajectory analyses since multilevel models are robust to missing data. This explains why there are more subjects included in the long-term follow up, than in the RCT. In total, 165 subjects answered both the baseline questionnaire and the long-term follow up. Of these subjects, 14 did not have a complete goal profile with goals set both in the questionnaire and with the rehabilitation team. This resulted in 151 subjects who were included in the descriptive analyses of goal profiles. Of the 151 subjects with a goal profile, four did not answer the discharge questionnaire including goal achievement. This resulted in 147 subjects included in the statistical analyses of goal achievement's effect on long-term outcome. Baseline characteristics of included subjects for all three papers are displayed in Table 1.

Subjects not consenting to participation had a mean age of 48 years (SD 13), 53 % were females, and 30 % had musculoskeletal disorders, without statistically significant differences compared to the consenting subjects. There were no statistically significant differences between the 36 subjects not completing outcome assessments and the 202 subjects completing assessments in the RCT or between the 32 subjects who dropped out during intervention and the 214 included subjects in the long-term trajectories. For the goal-setting analyses the 81 subjects who dropped out after consenting, did not differ significantly from the 165 included subjects.

Of the consenting subjects, rheumatic diseases were the most frequently reported musculoskeletal condition. Neurological conditions included cerebral palsy, multiple sclerosis and inherited motor neuron disorders as the most frequent. Cerebrovascular diseases, spinal cord injuries and visual impairments were among other reported conditions associated with disability. The median duration of disease that caused disability was 18.1 years.

**Table 1:** Baseline characteristics of subjects included in paper I-III.

| | **Paper I - RCT** (n=202) | | **Paper II** | **Paper III** |
|---|---|---|---|---|
| | Intervention (n=118) | Control (n=120) | **Trajectories** (n=214) | **Goal-setting** (n=151) |
| Age (mean) | 51 | 51 | 51 | 52 |
| Gender (female) % | 60 | 55 | 56 | 58 |
| Living in town/township % | 38 | 50 | 44 | 48 |
| Higher education (university/college) % | 43 | 51 | 44 | 47 |
| Employed % | 35 | 39 | 36 | 38 |
| Personal assistance (> 2h/week) % | 15 | 23 | 20 | 18 |
| Living alone % | 35 | 35 | 35 | 35 |
| Disability - Neurological % | 50 | 45 | 48 | 48 |
| - Musculoskeletal % | 27 | 30 | 30 | 29 |
| - Other % | 23 | 24 | 22 | 23 |

## Assessments

On admission to the rehabilitation center, the subjects had an interview with the physician where demographic data including age, gender, education, residence, employment, and need for personal assistance, were recorded. The main reason for disability (diagnosis) was gathered from the referral letter and validated by the physician at the admission appointment. Subjects were grouped according to disability because of disorders of the nervous system, disorders of the musculoskeletal system and other disorders.

*Self-reported physical and mental functioning* were measured by the Medical Outcomes Study 12-item Short Form Health Survey (SF-12, license number QM 027126) (135). The SF-12 consists of 12 items and yields a Physical Component Summary and Mental Component Summary, reflecting perceived physical and mental functioning, respectively. The answers were given on a Likert-type scale with 3 or 5 scoring levels for the different items. The Physical and Mental Component Summary (PCS and MCS) norm-based scores for the SF-12 were calculated using the reversed scores of questions 1, 8, 9 and 10 (136). Mean PCS and MCS for a Norwegian reference population are 50.3 (SD 8.8) for PCS and 50.6 (SD 9.9) for MCS (137). The scores were used for comparison of the study population's mean scores with a reference population without chronic disabilities. The SF-36 family of instruments was developed specifically to capture the broader burden of disease and the implications on functioning and well-being (128). They are the most widely used generic instruments and have been applied to more than 200 different medical conditions (138).

*Self-efficacy for managing chronic disease (Chronic disease-efficacy*) was measured by the Self-Efficacy for Managing Chronic Disease 6-Item Scale (139). The scale measures your confidence in the ability to manage symptoms like fatigue, pain and emotional distress, the ability to do things other than take medication to reduce the impact of illness and the ability to carry out tasks and activities in order to reduce the need to see a physician. The scale is a shortened form of the original Chronic Disease Self-Efficacy scales developed by Lorig et al. in 1996 (140) and contains items from the *manage disease in general* and *manage symptoms* subscales. A sample item is as follows: *How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?* Responses were given on a 10-point Likert-type scale ranging from *not at all confident* (1) to *totally confident* (10). The scale has been shown to be valid in a sample with 553 subjects with chronic disease and has demonstrated high internal consistency (0.93) (141).

*Self-efficacy for exercise regularly (Exercise-efficacy)* was measured by the Exercise Regularly Scale (3-item scale) which is a subscale in the original Chronic Disease Self-Efficacy Scales developed by Lorig et al. for the Stanford Chronic Disease Self-Management Program (140). A sample item is, *How confident are you that you can do aerobic exercise such as walking, swimming, or bicycling three to four times each week?* Responses were given on a 10-point Likert-type scale ranging from *not at all confident* (1) to *totally confident* (10). The scale has shown good validity in a sample with 478 subjects with chronic disease (the internal consistency was 0.83, and the test-retest reliability was 0.86) (140).

*Self-efficacy for social/recreational activities (Social-efficacy)* was measured by the Social/Recreational Activities scale (2-item scale) which is a subscale in the original Chronic Disease Self-Efficacy Scales developed by Lorig et al. for the Stanford Chronic Disease Self-Management Program (140). A sample item is, *How confident are you that you can continue to do your hobbies and recreation?* Responses were given on a 10-point Likert-type scale ranging from *not at all confident* (1) to *totally confident* (10). The scale has shown to be valid in a sample with 478 subjects with chronic disease (the internal consistency was 0.84, and the test-retest reliability was 0.84) (140).

*Pain* and *fatigue* were measured by visual analogue scales from 0-100 (VAS, 100 mm) (*no pain* to *intolerable pain* and for fatigue, *not a problem* to *a very big problem*) (142, 143).

*Motivation* towards physical activity and exercise was assessed by the 19-item Behavioral Regulation in Exercise Questionnaire (BREQ-2) (144). The questionnaire includes five subscales: Amotivation (four items) where a sample item is *I don't see why I should have to exercise*, external regulation (four items) where a sample item is *I exercise because other people say I should*, introjected regulation (three items) where a sample items is *I feel guilty when I don't exercise*, identified regulation (four items) where a sample item is *I value the benefits of exercise* and intrinsic regulation (four items) where a sample item is *I exercise because it's fun*. The items are scored on a five-point Likert scale (0-4) ranging from *Not true for me* to *Very true for me*. The BREQ-2 subscales *Identified regulation* and *Intrinsic regulation* are merged into the variable autonomous motivation. *External regulation* and *Introjected regulation* are merged into the variable controlled motivation (145). Mean item score is reported for each subscale. The scale was originally tested in a sample with 194 subjects, demonstrated to have an acceptable internal consistency and reliability was confirmed with Cronbach Alpha scores ranging from 0.73-0.86 for each item (144). The instrument has been tested in a Norwegian population of 120 overweight adolescents where it demonstrated acceptable fit and reliability was confirmed with Cronbach Alpha scores ranging from 0.71-0.86 for each item (146).

## Goal-setting

The subjects set one or two individual goals for the rehabilitation stay in the study questionnaire at admission before entering the facility. On the second day, as part of the clinical goal-setting practice, the rehabilitation team and the subject developed a goal-oriented plan for the rehabilitation including one to four negotiated goals. The goals were negotiated in a meeting were the subject sat down together with one or more health professionals from the rehabilitation team and discussed desired goals and possibilities ending with the final negotiated goals for the stay. Goal achievement was obtained through the written questionnaire at the last day of the rehabilitation stay (discharge), where the subjects were asked to rate achievement of individual goals on a numeric rating scale of ten points from "no achievement" to "full achievement". A mean score of the answer from the two goals was calculated for use in the analyses. See Figure 4 for a detailed presentation of the goal-setting process.

*Linking goals to the ICF*

Individual goals and negotiated goals were then linked to the ICF. The linking of goals was carried out as described in linking rules by Cieza et al (38, 96) and included three steps. First two raters separately selected one or more meaningful concepts out of the goals. In the second step the meaningful concepts were linked to one or more second level categories in the ICF. The linking was also done by two raters separately. If the information provided by the meaningful concept was not sufficient for deciding on a second level ICF-category, if the concept referred to health or quality of life in general, to a health condition, a personal factor or if the concept was not contained in the ICF, a descriptor code was assigned as described in the linking rules. Since the goals were in Norwegian language, the linking was performed using the Norwegian translation of the ICF. In the third step the coding of the two raters was compared. In cases of disagreement a third rater decided on the final code to reach consensus (Figure 4).

**Figure 4:** Detailed description of the goal-setting process

| | **Admission** | **After one week** | **Discharge** | **Linking to the ICF** |
|---|---|---|---|---|
| Negotiated goals in the patient journal | Physician and patient agree on 1-4 goals | Goals are revised in a multidisciplinary team meeting without the patient | Patient and the team have individual evaluations of the rehabilitation stay | Three-step process:<br>1. Two raters select one or more meaningful concepts out of the goals<br>2. The raters link the meaningful concepts to categories in the ICF<br>3. The two raters compare goals, in cases of disagreement a third rater decide on the final code |
| Individual goals in questionnaire | Q1: Can you write down the 2 most important goals for you stay at BHC | | Q1: To which extent did you achieve your first goal on a scale of 1-10?<br><br>Q2: To which extent did you achieve your second goal on a scale of 1-10? | |

*Comparing goal profiles*

Second level ICF-categories or descriptor codes linked from the different goals were compared to see if health personnel captured the categories linked from the individual goals.

## Sample size

The sample size was determined according to the change in mental and physical functioning (SF-12) previously observed in a study with a similar sample at BHC (147) (mean change in mental functioning was 8.26 with a SD of 9.97; mean change in physical functioning was 4.81 with a SD of 7.33). Adding a significance level of 5 % and power of 90 %, we needed 50 subjects in each group for the RCT, provided that there were no changes in the control group during the waiting period. Considering a possible 20 % improvement as a result of positive expectations among the control group during the waiting period (148), 70 people in each group were needed. Due to the nature of the admittance structure in the group rehabilitation at BHC, it was uncertainty around the number of non-consenters and drop-outs. In addition, we needed to adjust for possible confounders in the longitudinal analyses. Because of this we chose 150 subjects in each group as an estimate.

## Statistical methods

Data were analyzed using SPSS. A significance level of 0.05 was adopted. Descriptive statistics was used to describe the demographic and clinical characteristics of the groups, including intervention and control in the RCT. Dropout analyses were performed including T-tests.

*Paper I*

Differences on outcome between intervention and control groups were evaluated by multiple regression models. Dependent variables were changes in physical and mental functioning (PCS and MCS) from baseline to follow-up four weeks after rehabilitation. We adjusted for baseline PCS and MCS. Intention to treat analyses were conducted for subjects completing follow-up together with multiple imputation for all included subjects returning at least one questionnaire prior to the intervention.

For the intervention group, we calculated changes in pain, fatigue, motivation, exercise efficacy, social efficacy and chronic disease efficacy during rehabilitation. The impact of these changes for improvement in physical and mental functioning four weeks after rehabilitation was evaluated with multiple regression controlling for demographic factors and baseline PCS and MCS.

*Paper II*

Multilevel models (MLMs) were carried out to examine long-term trajectories of mental and physical functioning (PCS and MCS) and how they changed over the six time points for the subjects followed in the cohort.

First, two MLMs were performed to examine the linear trajectories of mental and physical functioning (MCS and PCS) with the predictors time, demographic factors, pain, fatigue, and self-efficacy. These MLMs study the general level of mental and physical functioning over the time period with predictors affecting the level. The variables were entered simultaneously as fixed effects into the models. For the purpose of the analysis all demographic variables were dichotomized and the disability categories were merged into two groups (those with nervous system disabilities and those with other disabilities). The respective mean was subtracted from all variables for the purpose of centering them before being entered into the MLM. PCS and MCS at each of the six time points (baseline, four weeks before admission, at admission to and discharge from rehabilitation, four weeks after discharge, and 12 months after discharge) were entered as the dependent variables in each model.

Second, a new set of two MLMs was run. Statistically significant predictors in the first models were included in order to examine whether they interacted with time in the prediction of subjects' physical and mental functioning trajectories. These MLMs study the change in mental and physical functioning over the time period with predictors affecting the change.

Last, predictors with significant interactions with time were dichotomized around their mean level (high/low), and paired sample *t*-tests were conducted to evaluate changes from baseline to the 12-month follow-up for subjects with high and low levels of the predictor.

*Paper III*

Multiple regression analyses were performed in order to explore effects of goal achievement on long-term mental and physical functioning. Dependent variables were mental and physical functioning (PCS and MCS) at 12 months. Reported goal achievement was included as a predictor. The models were adjusted for age, gender and baseline PCS and MCS.

# SUMMARY OF MAIN RESULTS

**Paper I**

*Does adapted physical activity-based rehabilitation improve mental and physical functioning?* published in *European Journal of Physical and Rehabilitation Medicine.*

This double blind, randomized controlled trial addressed the effects of APA-based rehabilitation by comparing subjects allocated a four-week intervention with the waiting list control group. Adults (18-73 years, men and women) with chronic disabilities who applied for a rehabilitation stay, were randomized.

Main outcome was evaluated regarding mental and physical functioning measured with the Medical outcomes study 12-item short-form health survey (SF-12) at baseline and four weeks after discharge. We also included measurements of self-efficacy, motivation, pain and fatigue to see if improvement in these parameters during rehabilitation and follow up was related to the main outcome of the intervention. Totally 202 subjects completed the follow-up and were included for analyzes.

Results indicated that, compared to waiting list, the APA-based intervention tailored statistically significant improvements in both physical and mental functioning. The improvement in functioning during rehabilitation was related to improved social-efficacy. The intervention group experienced significant improvement in social efficacy, chronic-disease efficacy and autonomous motivation, and significant decline in pain and fatigue during the rehabilitation period. The control group did not experience any change.

This paper was the first randomized controlled trial to evaluate APA-based rehabilitations in a mixed-case population with chronic disabilities. It concluded that the rehabilitation program improved functioning, suggesting that APA-based rehabilitation should be considered during the development of rehabilitation strategies for people with chronic disabilities. Motivational and self-efficacy aspects must be addressed when organizing and evaluating rehabilitation programs.

**Paper II**

*One-year trajectories of mental and physical functioning during and after rehabilitation among individuals with disabilities* published in *Health and Quality of Life Outcomes*

This paper addressed long-term mental and physical functioning before, during and following an APA-based rehabilitation program for subjects with chronic disabilities in a prospective cohort study following the RCT in paper I. We used multilevel modeling (MLM) to look at the trajectories of functioning for the whole time period when data was collected, which was at six different time points from eight weeks before admission at the rehabilitation facility till 12 months after discharge.

Adults (18-73 years, men and women) with chronic disabilities who applied for a rehabilitation stay, were included. MLM is robust to missing data resulting in 214 subjects in the study sample. Outcome on mental and physical functioning was measured by SF-12. It was also addressed whether demographic factors, reason for disability, pain, fatigue and self-efficacy at baseline, influenced the trajectories.

Results indicate that both mental and physical functioning improved during the time period and that the biggest improvement took place while admitted to rehabilitation. The trajectories also showed that low self-efficacy for managing chronic disease and high fatigue at baseline, as well as disability not associated with diseases of the nervous system, predicted a higher improvement in functioning. Having a low age, not needing personal assistance, a disability not associated with diseases of the nervous system, low pain and fatigue, and high self-efficacy for managing chronic disease predicted a high functioning throughout the time period.

This paper concluded that the improvement in functioning following an APA-based intervention found in the RCT in Paper I, was still significant 12 months after rehabilitation, even though the improvement had declined since the intervention. Subjects with high levels of fatigue, low self-efficacy for managing chronic disease and a disability not associated with diseases of the nervous system, had the greatest improvement. This has implications for the target groups when tailoring future rehabilitation programs.

In paper II, Table 1 presenting the demographic data of the included subjects there was a mix-up when making the table. Values given for subjects living in town (n=120, 56%) were the values for the subjects not living in town. This had no implications for the statistical analyses.

**Paper III**

*Individual rehabilitation goals; what is the content of the goals and do health professionals capture this content?*

This study was part of the prospective cohort study in paper II following the RCT in paper I. It addressed the content of individual goals set by subjects with chronic disabilities attending an APA-based rehabilitation program. It searched to compare these goals to the goals set by the same subjects in collaboration with the rehabilitation team at the facility to find out if health professionals capture the content of the individual goals. It also addressed goal achievement and its influence on long-term outcome of rehabilitation. The study sample consisted of 151 one subjects with a complete goal profile.

Goals were linked to the ICF for comparison. Individual goals were captured through a questionnaire at admission to the rehabilitation, while negotiated goals set with the rehabilitation team were captured from the medical journal. Goal achievement was measured through a questionnaire at discharge. Outcome on mental and physical functioning was measured with SF-12 at baseline and 12 months after discharge.

Results indicated that both the individual goals and the negotiated goals were most frequently linked to the ICF-component Body Functions with Activities and Participation being the second most frequently used component, used more frequently in the negotiated goals. The negotiated goals also had a higher relative frequency of concepts that could be linked to the ICF. The health professionals captured parts of the individual goal profile for 76% of the subjects. Totally, 66% of the 147 subjects who answered the questionnaire on goal achievement, listed a goal achievement of nine or more points out of ten on a ten-point numeric rating scale. Goal achievement was a significant predictor for long-term mental functioning following rehabilitation.

# DISCUSSION

## Methodological considerations

*Design*

When measuring effects of interventions there is a consensus that Randomized controlled trials (RCTs) are the gold standard (149, 150). In rehabilitation research, designing ethically acceptable and feasible RCTs may be challenging. Hence, the effects of rehabilitation interventions targeting the chronic disability populations, and particularly long-term effects, have seldom been evaluated according to scientific standards. A challenge when conduction RCTs is knowing if the intervention group actually do the things they are intended to do. In the RCT carried out at BHC this is fully controlled. The subjects attending rehabilitation is closely followed by health professionals and their activity and progress is registered making it impossible to sneak away from the intervention when you are first admitted, except if you actually drop out and leave the facility.

*Quality criteria for rating studies of cognitive rehabilitation.*

In 2009 Cicerone et al published an evaluation of the methodological quality of research on rehabilitation after TBI (151). This work resulted in a checklist of "quality criteria for rating studies of cognitive rehabilitation" containing 16 primary criteria for evaluating the quality of RCTs. Eight criteria relate to the internal validity of studies, five are descriptive criteria and three are statistical criteria. The checklist enables a clear judging of methodological quality when evaluating rehabilitation research. In the following I will go through the criteria in the checklist to evaluate the present study.

1. Internal validity

*A "Inclusion and exclusion criteria were explicitly stated".*

Inclusion criteria: Chronic disability as defined by WHO, aged 18 to 73 years (men and women) and admitted to a four-week rehabilitation stay at BHC.

Exclusion criteria: Insufficient knowledge of Norwegian to fill out the questionnaires and severe cognitive disorders.

These criteria are explicitly stated.

*Bi. "Randomization: An unpredictable random sequence was used to assign participants to treatment condition. The method of randomization was adequately specified. Quasi-random methods do not receive credit.*

*Bii. Allocation of participants to condition was concealed from the investigators, achieved through one of the following methods of assignment to treatment:*

- *An independent person who is not responsible for determining the eligibility of participants and who has no information about the person participating in the trial*
- *A centralized randomization scheme, e.g. a computer system providing allocations in a locked unreadable file that could be assessed only after inputting the characteristics of an enrolled participant.*
- *Randomization order is predetermined and individual assignments are maintained in sequentially numbered or coded sealed opaque containers until after the participant is enrolled."*

The subjects were randomized to rehabilitation or a waiting list control group. The control group did not receive any intervention during the waiting period, but were assigned to receive rehabilitation after the primary outcome evaluation of the study. Sequentially numbered, opaque, and sealed envelopes were prepared according to the randomization scheme generated by the web-site Randomisation.com. Randomization was performed in blocks of 30. A secretary who was blinded to the intention of the study enrolled the participants according to the information in the envelopes. The randomization was concealed from the participants, the researchers and the staff members who treated the participants. The randomization code was broken after the data analyses were finalized, i.e. after the primary outcome was assessed.

*C. Baseline characteristics: The participants in different treatment conditions should be comparable at start of treatment on important characteristics, such as demographic variables (age, sex, education), injury severity, time since injury, severity of impairment, and value of the primary outcome measure. Characteristics of both the experimental and control groups must be described to receive credit.*

Characteristics of the intervention and control groups were given and compared without significant differences ($p>0.05$). The baseline characteristics used for comparison were age, gender, if living in town, higher education, employment status, personal assistance, if living alone and diagnostic reason for disability. Values of primary outcome measures (SF-12 PCS and MCS) were also compared.

*D. Description of interventions: Adequate information is provided describing both the experimental and control interventions, allowing the reader to understand the rationale both for the intervention and for the comparison of experimental and control conditions. To receive credit for this item, all of the following criteria must be met:*

- *Experimental intervention*
    1. *The nature of the intervention is described in sufficient detail to understand how the interventions were provided (e.g., individual or group) and the methods used to promote change (e.g., repetitive practice of exercises, development of compensatory strategies).*

       The nature of the intervention is described in detail including the group-setting with individual schedules made after goal-setting, the activities offered and the APA-theory as basis for the methods used.
    2. *The total duration of treatment is provided, either in terms of length of treatment or termination criteria.*

       The total duration of four weeks is provided and repeated.
    3. *The intensity of treatment is provided, in terms of hours, number of sessions, frequency of sessions, and so forth.*

       The intensity is described in terms of hours a day and days a week including a specific description of the intensity of physical activity, teaching programs and social or cultural activities.
- *Control intervention*
    1. *For no-treatment conditions (including wait-list controls), duration of the nontreatment or wait-list condition should be equivalent to duration of the experimental treatment.*

       The duration of waiting-list condition was equivalent to duration of the experimental treatment with a 4-week "treatment period" and a 4-week follow up. This in not explicitly described in the study paper.
    2. *For alternative treatment conditions, the nature of the control intervention is described as outlined for "Experimental intervention."*

*E. Cointerventions: Adequate information is provided as to possible exposure to alternative treatments or cointerventions (outside of the study design), both for the treatment and for the no-treatment control conditions (if any).*

The waiting-list control group did not receive any interventions during the waiting period, information about this is provided. The waiting-list control group were situated in their local

environment and did not know that they were on a waiting list. One could not tell them to not engage in activities that might be seen as alternative treatments in this period because it would have broken the blinding. We expected that subjects in the waiting list group continued activities they were already doing. Some might have engaged in new activities, but we do not have any data confirming this. The intervention group is situated at the rehabilitation facility throughout the rehabilitation. All activities offered at this facility is included in the intervention so it is not possible for this group to receive any alternative treatments or co-interventions while at the facility. For the period from baseline to intervention and the four weeks of follow up after intervention, this group is also in their local environment and we cannot control the span of activities or treatments they are doing. As a result, we cannot say that there were no co-interventions or treatments going on for the subjects in both groups when situated in their local environment. This might influence the results of the present study.

*F. Outcome assessor blinded: In order to receive credit, both (1) the person conducting the outcome assessment should be unaware of the participant's treatment condition, and (2) objective outcome measures are used, including objective neuropsychologic measures, standardized structured interviews, or standardized clinical rating. If only self-report by the participant is used, and the participant is aware of his/her assignment to treatment condition, no credit is given.*

The study uses only self-reported outcome measurements. The participants are not aware of their assignment to treatment condition when answering.

*G. Outcome measures should be congruent with the intended effects of the intervention. For cognitive rehabilitation, such measures might include (1) measures of cognitive impairment, including standardized neuropsychologic assessment or other standardized or experimental measures of cognitive-linguistic functioning; (2) neurobehavioral or psychosocial symptoms; (3) assessment of activity limitations; (4) measures of participation, community integration, or employment; and (5) quality of life and subjective well-being.*

APA-theory focuses on adapting activities to increase physical activity and participation. BHC focuses on activity and participation through life. Valid outcome measures on participation in a generic disability population is lacking and measuring mental and physical functioning as primary outcome was the instrument most congruent with the intended effects of the intervention. One can ask if an objective (not self-reported) measurement of physical activity or endurance could be applied. This would add interesting information of physical fitness, but doing measurements of participants in their home environment at baseline and at follow up all over Norway would demand many assessors and possibilities for bias. Also,

physical fitness or endurance is by no means reflecting a person's feeling of participation which is the intended outcome.

2. Descriptive criteria.

*H. Withdrawal and dropout rates: Participants included in the study but who did not complete the observation period or were not included in the analyses must be described, and reasons for withdrawal should be provided. If the percentage of withdrawals and dropouts does not exceed 20% for short-term outcome and 30% for long-term outcome and does not lead to substantial bias, a "yes" is scored.*

The flow of participants from eligible to consenting and from consenting to follow up, were described in detail including dropout analyses. The percentage of dropouts after consenting was 17.9%. In Norway the participants in studies are allowed to withdraw without giving reason. According to the Regional Committee for Medical Research Ethics, reasons for withdrawal is not allowed to be published in research.

*I. Short-term outcome assessment is conducted at the end of the intervention period or within 3 months of the end of treatment and is reported and analyzed within the article.*

Short-term outcome assessment was conducted four weeks after the end of the intervention period. This is reported and analyzed within the article.

*J. Long-term outcome measurement was conducted more than 3 months after completion of treatment and is reported and analyzed within the article.*

Long-term outcome was not assessed in the RCT. The blinding was only possible to keep for the short-term follow-up after four weeks. Ideally one would want to do follow-up for 12 months with a control group to be able to compare also when looking at long-term effects. It would hardly be ethical to keep the participants on a 12-month waiting list. In addition, the participants would not be blinded any more, as it is not possible to wait for 12 months without noticing that you are the one waiting. This would also affect the blinding of the health professionals since the participants would probably complain to them about the long waiting time when arriving at the rehabilitation facility.

*K. Timing of outcome assessment should be identical for all intervention groups and for all important outcome assessments.*

The outcome assessment is measured by questionnaires administered to all participants at the same time-points ensuring identical timing.

*L. Sample size should be stated for each group at randomization and/or at the beginning of the intervention. There is no pre-set cut-off point to determine whether sample size is sufficient.*

Sample size for each group is stated in the article and was determined considering improvement in waiting-list as a result of expectations, drop-out and confounders.

3. Statistical criteria

*M. ITT analysis: All randomized patients are reported and analyzed, other than missing values. Patients who withdrew after randomization but prior to baseline observations should be identified; all patients who received the baseline evaluation should be included in the pre-post treatment analyses to receive credit for this item. Alternative analyses may also be conducted, particularly if dropout is greater than 20%. Observational studies do not receive credit for this item because of the inability to assess withdrawals from treatment accurately.*

Intention-to-treat analysis were conducted for subjects completing follow-up together with multiple imputation for all included subjects returning the questionnaire prior to the intervention. This does not include all randomized participants because randomization was conducted before the participants consented and we do not have data for subjects not consenting to be part of the study and data collection. The timing of the randomization is a weakness of this study.

*N. Both point estimates and measures of variability should be presented for one or more relevant outcome measures. Dichotomous data or frequency data (e.g., number of participants who return to work) should typically include ranges or confidence intervals to receive credit for this item.*

All outcome measures are presented as point estimates. Variability is presented through confidence intervals or standard deviations.

*O. Statistical comparison of treatment effect: The statistical analyses must include a direct comparison between treatment conditions and not just report change for each treatment group (within-group effects). Between-group analyses of outcome that do not include a group x time interaction effect are acceptable, as long as there is evidence of no difference between groups at baseline. If multiple outcome measures are used, and not all are statistically analyzed, credit for this item is based on statistical analysis of the primary outcome measure.*

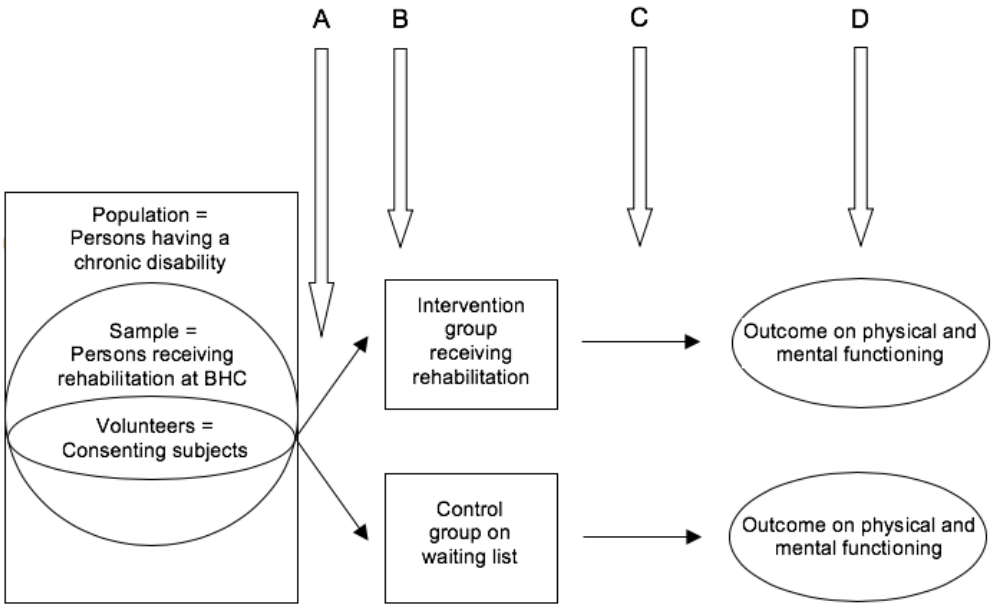
Change in primary outcome data from baseline to follow-up is compared directly for the intervention and treatment groups using multiple regression models.

*External validity in RCTs*

RCTs often have lower external validity than other study designs (152-154), usually due to strict inclusion and exclusion criteria. In addition, the participants may reject to attend. Sometimes the rejection may be related to particular preferences for treatment. In such cases the Zelen's design, where subjects consent to participate after randomization and ended intervention, is a possibility (155). The result on validity is that the participants included in RCTs may not be comparable with the population attending general rehabilitation (156) (Figure 5). In the present study subjects with cognitive problems were excluded and about one third of the eligible subjects did not attend. We cannot completely exclude that this third may respond differently.

**Figure 5**. The volunteers in an RCT is only a tiny portion of the population. Even though you secure that the sample is a random selection of the population, the portion that consent to participate might not be. Hence dropout analyses are important(157).

A. Randomization and allocation concealment
B. Actual assignment that can be followed by masking subjects as to their assigned group
C. Prospective evaluation period during which health care providers, investigators, and/or external monitoring committees can be masked as to the subjects assigned group
D. Outcome evaluation or adjudication during which outcome assessors can be masked as to the subjects' assigned group



*Population and dropouts*

Another challenge is different magnitude of drop-out in the intervention arms. This was the case in the present study's RCT, with higher drop-out in the intervention than in the waiting list group. In Norway the participants in studies are allowed to withdraw without giving reason. We could only speculate that the dropout it is a time effect, but of course we cannot exclude that non-responders dropped out and thereby contribute to a conclusion on a more effective intervention than it really is (Figure 5). Furthermore, the participants of this intervention are a case mix in diagnoses and disability profile. Hence, the results apply to different disability groups.

Finally, the subjects included in this study are comparable to the general adult population at BHC. But the people attending rehabilitation at BHC differ from the people with a chronic physical disability in general in several ways. It is a voluntary decision to participate in a rehabilitation stay. The subjects choosing this might be more motivated to improve their functional skills and physical capacity, as well as to meet new people in such an environment. A more positive attitude towards physical activity can be expected in the people attending rehabilitation at BHC, because they are well informed about the treatment program at the rehabilitation institution before choosing to apply for it. They also have to be able to leave their everyday environment, family and work situation for a period of four weeks to attend rehabilitation. This might weaken the external validity of the study. The subjects included in the study have approximately the same higher education level as the Norwegian population in the same age group(158). They do have a higher education level than the Norwegian population with disabilities(159), but the two groups differentiate in cognitive capabilities (BHC caters rehabilitation mainly to adults with physical disabilities and severe cognitive disorders is an exclusion criterion in the study), meaning they are not comparable.

*Assessments*

When choosing outcome measures it is important to find measures capturing as many meaningful components as possible which is challenging in the complexity of rehabilitation interventions. One is not able to know if they have captured all components of importance. There might be components we are unaware of or unable to measure. Self-reported measures are widely used and important in rehabilitation where the individual opinion is of major importance. However, self-reported physical functioning is not directly related to more

objective measurements like force, endurance or maximal oxygen uptake. In this study all measures are self-reported.

We have used the term functioning to describe The Medical Outcome Studies Short-Form Mental and Physical Component Summaries (MCS and PCS). In the literature you can find terms, such as mental and physical health, mental and physical functioning, and health-related quality of life describing the same component scores (147, 160, 161). The ability of this type of instrument to reflect relevant changes in chronic disabilities has been debated (162) and it has also been debated whether quality of life is a good term regarding the content of these measurements (163). The present study supports the feasibility of the SF-12 instrument, at least when viewed as a measure of functioning. These instruments are generally well evaluated regarding reliability and responsiveness (135). The SF-12 is a far less time-consuming short form of the SF-36. In previous studies it has been regarded as easier to complete and was chosen to increase the response rate after discharge and retain the explained variance (135, 137). The SF-12 has been shown to capture approximately 90% of the variance in the SF-36 and to reflect the same eight dimensions (137). The limitation of the SF-12 is that only physical and mental component scores can be evaluated, while one can evaluate the dimension scores with the SF-36.

We also tried to assess factors targeted by the intervention and assumed to influence outcome. Measurements of motivation and self-efficacy are less validated than the measurements of functioning. Their responsiveness and effect sizes are generally not studied. However, we chose a self-efficacy instrument that at least was evaluated in terms of test re-test validation (140). There are not many standardized measurements of motivation available, none of them are aimed specifically at persons with a disability. The motivation instrument chosen covers the whole motivation aspects with its five subscales amotivation, external regulation, introjected regulation, identified regulation and intrinsic regulation. It is tested with acceptable internal consistency and reliability and has also been tested in a Norwegian population (144, 146).

Overall fatigue was measured by VAS on a scale of 0-100. The study did not explore the different aspects of fatigue, i.e. subjective mental and physical fatigue. Fatigue is challenging to study partly because there is a lack of a commonly accepted definition of fatigue leading to problems when creating measurements (164).

*Data collection*

The data collection at admission and discharge occurred at the rehabilitation facility, while data from all other time points were collected in the subjects' home environment. We observed that the measurements collected in the participants' local environment and at the center differed; hence they are not directly comparable. The benefit of subjects completing measures during the rehabilitation stay was increased number of forms completed, and also the possibility to evaluate change during the intervention period.

*Goal-setting*

Comparing the individual goals set at the questionnaire with the negotiated goals set by health professionals after talking to the subjects, might raise some methodological issues. One may argue that they are set in totally different settings, making them non-comparable. Still, the two different ways of setting goals reflects interesting aspects of goal-setting. The individual goals are set only by the subjects in written form at a questionnaire, without any influence from health professionals or through an interview, with no education in goal-setting theory. The negotiated goals are still influenced by the individual's needs, if the subjects actually did tell the health professionals the goals they believed were important. They are also influenced by people who know the content of the intervention regarding what it is possible to learn and achieve and who knows goal-setting theory. To compare these two ways of setting goals is a way of getting to know what happens when health professionals involve themselves in the not health-profession-educated thoughts of the subject.

When investigating the goal-setting process in this study, we are evaluating the process the way it is carried out at the rehabilitation facility today, as a basis for possible change. Still, the study does not manage to investigate the goal negotiating process in detail, it only compares the final products of the two different processes. It would be interesting to further look into what is actually happening when patients and health professionals are setting goals together. This might require a different methodological approach, an issue that could have been uncovered if we had done a pilot prior to the main study.

Since we have no insight to what happened in the negotiating process, we do not know why the goals change. It could e.g. be as a result of the health professionals specifying the goals, of the desired activity not offered in the intervention, of reality checks of goals too hard to achieve or even as a result of the subjects not communicating their individual goals to the

health professionals. Reasons for the change in goal profile and non-capturing of individual goals is seldomly studied and methodologically challenging.

The linking of goals to the ICF raises methodological issues. It is challenging to decide how specific one should be when linking the meaningful concepts to the ICF. To ensure reliability, personal interpretations must be left out of the linking. The linkers knew the setting at BHC well, this might lead to a broader understanding of the subjects' intentions regarding the goals and meaningful concepts. This understanding could not be used when linking. To the best of our effort, the concepts where read straight forward without interpretation. In order to include the context into the goals, one would have needed for the goals to be more specific or to be able to register the negotiation in detail through observational qualitative studies.

In the present study we measured goal achievement on a numeric rating scale from 1-10, without a validated cutoff value. A numeric rating scale was chosen to measure goal achievement because it is quick, convenient, and easy to understand. Using a standardized validated measure like GAS may have been a better fit. GAS is a time-consuming measure requiring adequately trained health personnel in the performance of the measure. The present study observed and described the goal-setting process at BHC "as is", where GAS is only used for the goal-setting in children attending rehabilitation (165). There is a lack of validated simple tools to measure goal achievement. GAS is complex, but may be the best existing validated tool. To strengthen the methodological approach of the present study it would have been an advantage to validate the numeric rating scale to GAS.

## Ethical considerations

Waiting list is used as control group in the RCT conducted in this thesis, meaning that the subjects randomized to control group got delayed intervention and had to wait eight weeks to receive the rehabilitation they were allocated to. This might raise ethical issues. However, in the present study both groups received the intervention within the general waiting time for rehabilitation at BHC. This would not be the case for the long-term follow-up and was the main reason why we did not extend the RCT to last through the whole follow-up period of 12 months. Considering the group had a median duration of disease that caused disability of 18.1 years, eight more weeks before receiving treatment will not be of great impact. More than a year of being on a waiting list was on the other hand seen as unethical.

## General discussion

*Effects of APA-based rehabilitation on mental and physical functioning*

The first aim of the thesis was to evaluate the effects of adapted physical activity-based rehabilitation on mental and physical functioning for subjects with chronic disabilities. The results presented in Paper I indicate effects of APA-based rehabilitation on short-term physical and mental functioning, with stable values in the waiting list control group. Results presented in Paper II indicate that improvement remained statistically significant at the 12-month follow-up.

This supports previous findings indicating an association between rehabilitation and improvement in mental and physical functioning up to three months after rehabilitation (147, 166) and provides new knowledge about the long-term effects of rehabilitation. To the best of our knowledge, this is the first randomized trial to evaluate APA-based rehabilitation in a mixed-case population with chronic disabilities. A number of randomized controlled trials have found that interventions based on physical activity and exercise and directed towards patients with cardiovascular and other lifestyle disorders, have positive effects on functioning (129-131). Roine et al. (167) reviewed 151 articles applying exercise interventions to a wide range of conditions. The review concluded that exercise improved quality of life and was cost-effective for treating both musculoskeletal and cardiac conditions. It is also well known that patients with neurological disorders seem to benefit from physical activity, Motl et al. (168) followed a sample with multiple sclerosis and found that interventions promoting physical activity improved physical functioning after six months. Furthermore, Tallner et al (169) studied the association between physical activity and the mental components of the SF-36 in patients with multiple sclerosis. They concluded that physical activity was associated with better mental functioning even when limitations of physical functioning were accounted for. When following patients with multiple sclerosis for a longer time period, where one would expect a decline in physical functioning following the nature of the disease, research reveals that physical activity was associated with a reduced decline in physical functioning over a five-year period (170). In summary, previous research supports the findings of this thesis suggesting that physical activity is beneficial for functioning both in a short- and long-term perspective.

*Factors related to the effects on physical and mental functioning*

The second aim was to determine whether demographic factors, reason for disability, pain, fatigue, motivation, self-efficacy and goal achievement influenced outcome on functioning.

Results presented in paper I suggests that motivation and self-efficacy improved while pain and fatigue decreased during the rehabilitation. The control group did not report these changes during the waiting list period. Improvement in self-efficacy is observed in other rehabilitation interventions (139, 171). In the present study, the APA-based intervention aimed to improve self-efficacy through positive experiences with physical as well as social and cultural activities. Results indicate that improving social-efficacy seemed to be an important factor for the improvement in physical and mental functioning. This is supported by the results of earlier studies that demonstrated a relationship between health status and self-efficacy (139). The results suggest that self-efficacy is a state with potential for modification. The effect of physical activity on pain and fatigue is also previously well documented (19, 23).

In paper II we studied the predictors influence on long-term changes in functioning. Results indicate that subjects with low chronic disease-efficacy at baseline had significantly greater improvement in both mental and physical functioning over time than subjects with high chronic disease-efficacy, who did not have a significant improvement in neither physical nor mental functioning at 12-months follow-up. The two groups had almost the same improvement in physical functioning during rehabilitation, but the high chronic disease-efficacy group had a greater decline in functioning from discharge to 12-month follow up. The results suggest that the intervention might influence subjects with low self-efficacy for managing their chronic disease in a way that not only improves their physical functioning during rehabilitation, but help them sustain this improvement in a better way than it does for the group of subjects with high chronic disease-efficacy. An explanation to how this works could be that the subjects with low chronic disease-efficacy started their rehabilitation with much insecurity about managing their disease, a trait that could hold them back with regard to improvement. After some time in the BHC environment, it appeared as though they became more secure and observed that others could manage the same disease and activities. This improvement in security might be one of the things they brought back to their local environment helping them maintain their physical and mental functioning for the long-term follow-up. It is important to notice that these explanations are only assumptions. The present study did not investigate reasons for the maintenance of functioning after discharge, but it is

likely that the intervention is a factor. The effects could also be the result of statistical regression to the mean over time, whereby participants with a low efficacy at baseline have the lowest levels of physical and mental functioning and the most room for improvement in functioning during rehabilitation. The fact that subjects with low chronic disease-efficacy at baseline had a greater improvement in functioning was also stated in a previous study on individuals with neuromuscular diseases and multiple sclerosis (172), although that study measured outcome over a shorter time period.

Furthermore, subjects with high levels of fatigue at baseline, had a significantly greater improvement in mental functioning over time than subjects with low levels of fatigue, who did not have a significant improvement at 12-months follow-up. The biggest improvement in mental functioning happened during the intervention period where both groups improved, the high fatigue group a lot more than the low fatigue group. The high-fatigue group degraded more than the low-fatigue group after discharge, but because of the big improvement during rehabilitation, it was still significant at the 12-month follow-up. The results are suggesting that the intervention tailored an improvement in mental functioning to a greater extent for subjects with fatigue than subjects without fatigue. It is well known that fatigue leads to a reduced functioning (173-175), the findings of this study indicate that APA-based rehabilitations might be a way to limit the reduction in mental functioning. The result also supports the findings of previous studies that investigated the association between fatigue and functioning (166, 176).

Paper III assessed goal achievement during the intervention as a possible factor related to functioning. Results indicated a significant effect of goal achievement on long-term improvement in mental functioning 12 months after rehabilitation. To the authors knowledge this is the first study investigating the effects of goal achievement on outcome of a physical activity-based rehabilitation for a sample with chronic disabilities using standardized outcome measures. Previous studies carried out to investigate goal achievement support the findings on the effect of goal achievement on outcome. Brock et al. (177) found that stroke survivors who achieved their goals during post-acute inpatient rehabilitation, were less likely to be depressed, showed stronger self-efficacy beliefs and more positive perceptions of their participation in everyday and community life six months after discharge. Hazard et al. (178) studied a sample with chronic disabling spinal disorders and found that satisfaction with progress after rehabilitation was more strongly related to goal achievement than more

traditional outcome measures, suggesting that goal achievement should be considered also as a measure of outcome after rehabilitation. They did not use a standardized measure of patient satisfaction. Coffey et.al. (179) used a standardized outcome measure on a sample of lower limb amputees in post-acute inpatient care. They found that stronger goal pursuit and goal adjustment tendencies on admission predicted lower disability and higher quality of life six months post discharge, but they did not investigate goal achievement.

It is interesting that the mental functioning and not the physical functioning is improved by achieving goals set in a rehabilitation setting focusing on physical activity. A possible explanation can be found in Self-Determination Theory, where satisfaction of needs for autonomy, competence, and relatedness is a universal requirement for psychological well-being (180). Goal achievement will most likely lead to needs satisfaction, leading to psychological well-being which is closely connected to mental health and functioning. The positive connection between needs satisfaction and SF-12 mental functioning is demonstrated in a previous study at BHC (181).

*Comparing the observed levels of functioning to the non-disabled population*

The overall level of physical functioning in our study sample was considerably lower than the non-disabled population (137). This gap in physical functioning between the disabled population and the able-bodied population is well-known (182, 183). Although our sample had a significant improvement in physical functioning from baseline to discharge, physical functioning was still 15% below the reference population. This is expected considering previous research and the nature of the disability in subjects referred to rehabilitation at BHC. Our sample's baseline mental functioning did not differ from that of the general population (137). This is an interesting finding supported by previous studies on populations with disabilities (182, 184, 185). Considering the difficulties a person with disabilities face, it is hard to imagine that it does not affect their mental functioning. The mental consequences of physical disability vary largely (186, 187), and it is possible that subjects referred to rehabilitation institutions like BHC have a better mental functioning than the rest of the disabled population. During the four-week intervention carried out in the present study, the sample's mental functioning rose to a higher level than the reference population. BHC may be a perfect setting to improve mental functioning for subjects with disabilities, as it is an environment away from everyday life struggles, bringing together people who have similar

disabilities and health problems, creating social interaction. It is reasonable to suggest that these social cofactors might also be active ingredients contributing to the observed improvement in mental functioning. The clinical significance of this improvement is difficult to evaluate because the participants had normal mental functioning before their admission.

*Goal-setting*

The last aim concerned identification of the content of goals set among individuals attending rehabilitation and comparing them to negotiated goals set in collaboration with the rehabilitation team to see if health professionals captured the content of the individual goals.

Results presented in paper III show that both the individual goals and the negotiated goals were most frequently linked to the ICF-component Body Functions. After negotiation, the goals were more frequently linked to the ICF-component Activities and Participation and they were more frequently possible to link to ICF-codes.

Previous research supports the findings that health professionals tend to set impairment goals linked to the ICF-component Body Functions, but differs from the findings that this is also the case for the individual goals (102). When it comes to patient set goals, previous studies indicate that they tend to set goals linked to Activities and Participation-component of the ICF (102, 107, 108). The focus at BHC is on increasing participation through increased physical activity, a focus known for the subjects at admittance when setting goals. It might lead to the understanding that improving strength and endurance is the desired goal in order to increase physical activity levels.

The frequent use of impairment goals, can also be a result of the close connection between goal-setting and active ingredients in rehabilitation. Goals set by health professionals are often interpreted as treatment interventions, one can see them as stepping stones towards a more complex goal at the activity and participation level (104). This difference between the means and the ends in goal setting, introduces the terms *learning goals* and *performance goals*, presented by Benzer et al as an answer to the term “goals gone wild” (188). Learning goals reflect the means, the action goals, the stepping stones. Performance goals reflect the ends, the more complex goals. The researchers propose that we might need both these goal

types in a rehabilitation goal-setting process seen the complexity of disability and rehabilitation interventions (188).

Learning goals focus on acquiring *activity competence*, the ability to execute the activity being undertaken according to an expected standard as described by Imms et al. in their participation model (115). This research group propose that there is little direct effect on participation of interventions focused at the level of body function or activity performance, suggesting that a more direct approach to changing participation is more likely to have an effect on participation as an outcome (121). To increase participation, it is important to include not only the means, but also the ends into goal-setting. Even though they are complex goals and might be harder to measure, performance goals should be included in every goal-setting process.

The negotiated goals were more easily linked to the ICF. The experience of the researchers linking goals in this study, was that many of the extracted meaningful concepts regarded physical health and exercise in a general manner and could not be linked because they were too vague. This supports previous findings that patients tend to express themselves in general phrases resulting in goals too wide to link to the ICF (107, 112). An important role of the health professionals is to specify the goals, by digging into what the patients really mean by improving general health or by breaking the goals down into smaller constructs, still ensuring they are goals owned by the patient (107, 112, 113, 189). Even though the negotiated goals were more easily linked to the ICF, the wide exercise and health goals that could not be linked and given the descriptor code *ndph* remained at the same level for both the individual goals and the negotiated goals. The other descriptor codes given to individual goals that could not be linked, decreased drastically. These results indicate that health professionals at BHC are better at specifying goals, but not goals regarding physical health and exercise in general. An explanation to why the negotiated goals were more easily linked to the ICF, is that health personnel working at BHC are familiar with the ICF and use the ICF in their clinical practice. Integrating the ICF in clinical goal-setting practice has been proposed as a way of standardizing goal-setting processes and making goal-setting easier to use in outcome evaluation, it also provides an implementation framework promoting collaboration (108, 190).

The ICF-category most frequently used when linking the negotiated goals, was *d155 Acquiring skills.* Meaningful concepts regarding getting to know and learning to manage new

activities were linked in this category. This is in line with one of the main focuses of the rehabilitation at BHC being activity competence, to gain knowledge of and learn to manage activities that can be transferred to the subject's local environment. Acquiring the competence required to manage an activity is an equally or even more important learning goal than improving muscle power and endurance, when the endpoint is increased participation (115, 121). Another main focus of BHC is adaptation of activity equipment. To some it may be surprising that components in the ICF-category environmental factors are almost absent in the goals set both by individuals alone and in collaboration with the team. Adaptation of equipment and using equipment to be active are not goals, but examples of active ingredients needed to reach the main goal which, in this case, is the activity. If the goal is to learn how to ride a bike, adapting the bike is not the goal, but an ingredient needed, a stepping stone towards reaching the goal.

When it comes to health professionals capturing of individual goals, three quarters of the subjects' experienced that at least one of the ICF-categories or descriptor codes from their individual goals were captured in the negotiated goals. For 25% of the subjects, none of their goals were captured. Possible explanations are that categories might change due to specifying in the negotiating process, the individual goal might not be achievable with the rehabilitation offered or the goal might not be realistically achieved. Even though health professionals encourage hard goals because they lead to higher task performance (91), they will not encourage goals clearly not possible to achieve. Instead they will try to modify these goals.

*Evaluating complex interventions*

Rehabilitation interventions are complex interventions, conventionally defined as interventions that contain several interacting components (50). As stated, knowledge of the effective elements of these interventions is insufficient (191). Understanding the features of the intervention regarding which active ingredients actually contributes to the effect, is challenging and in need of further investigation. The effective elements are both related to the intervention and specific to the individual. Interactions between the components are known to be a success criterion (85). A reductionist approach with studying the components' impact separately is often taken, but has a risk. It may well be that the beneficial effect of each intervention is magnified by the effect of other interventions in the rehabilitation process. The

isolated effect of each part may be too small to detect. This is the core of the *black box of rehabilitation* (52).

Craig et al. published *Medical Research Council* Guidance to developing and evaluation complex interventions in 2008 (50). The guidance is not rehabilitation research specific, but is regarding all complex interventions. In the guidance they ask "How do the intervention work? What are the active ingredients and how are they exerting their effect?". They pinpoint three aspects regarding evaluation of complex interventions. The first is *Assessing effectiveness* where randomization should be considered because it prevents selection bias. The second is *Measuring outcome* where one should ask "Which outcomes are most important?" and "Which sources of variations in outcomes matter?". To answer the latter appropriate subgroup analyses are preferred. To study whether short time changes persist and whether outcomes predicted by interim or surrogate measures do occur, long-term follow up might be needed. The last aspect in the guidance is *Understanding processes* to gain insight into why an intervention fails or how a successful intervention works and how it can be optimized. To do this you need a process evaluation nested inside the trial. The process evaluation assesses fidelity and quality of implementation, clarifies causal mechanisms and identifies contextual factors associated with variation in outcomes. The variability in implementation makes it important that both process and outcome evaluations are reported fully, and that a clear description of the intervention is provided in order to enable replication and synthesis of evidence (50).

In light of this guidance the study carried out in this thesis is assessing effectiveness by carrying out a randomized trial. It is measuring outcome with a clear understanding of the importance of the primary outcomes chosen, and it includes subgroup analyses to study variations in outcome as well as long-term follow up in order to study whether short time changes persist. When it comes to understanding processes, the study might not fully understand the processes leading up to the outcomes that are found. The active ingredients are to some extent well known and reported in the description of the intervention alongside with the findings on i.e. goal-setting. Still, a process evaluation nested inside the trial as described by Craig et al., was not carried out. It is important to be aware that some of the ingredients leading to the outcome found may be related to a synergic effect between participants not inherent to the intervention itself or by other active ingredients not known to this point. As a result, we still do not fully know how the intervention works and how it can be optimized.

Given the notion on public involvement and patient-oriented research, involving the users of the rehabilitation service to a greater extent, for example by using qualitative approaches including interviews and observation in activity and interaction, might be an idea for process evaluations in order to further explore the active ingredients and processes leading to the detected outcome.

Even though this thesis is not evaluating outcome on participation directly, several aspects from the *family of participation-related constructs* are addressed. The model presents three intrinsic factors of participation – activity competence, sense-of-self and preferences. Gaining activity competence is an important part of the intervention at BHC and a factor that also seems important to the study sample with acquiring skills as one of the most frequently used ICF-codes linked out of their goals. To capture sense of self, self-efficacy might be a valuable measure and research also suggests that self-efficacy is closely correlated to preferences, meaning self-efficacy is a possible contributor to participation (192). Self-efficacy for managing chronic disease and self-efficacy for social and recreational activities improved during rehabilitation in the intervention group of our sample, these improvements might lead to improved participation following the rehabilitation stay.

Previous research carried out at BHC have tried to measure participation for children attending rehabilitation. Willis et al. (165) measured attainment of participation goals set both for the rehabilitation period and for the follow-up period, using GAS and the Canadian Occupational Performance Measure (COPM). They found significant improvements in the rating of these goals. Results also indicated that environmental factors were the most frequent barrier to goal attainment following rehabilitation. Nyquist et al. (193) interviewed eleven children attending rehabilitation at BHC on perspective of participation. Results indicated that to practice and learn physical activities during a rehabilitation stay, seemed to enhance transferring of meaningful participation to the local environment, and was related to the children's activity competence, preferences and self-efficacy. Baksjøberget et al. (194) used The Children's Assessment of Participation and Enjoyment (CAPE) in investigating change in the participation profile of physical activity during the 15 months following rehabilitation at BHC. They found declines in participation diversity and intensity of all leisure activities included, but a stable participation level in physical activity indicating rehabilitation at BHC impacts long-term participation in physical activity. Gjessing et al (195) investigated the impact of use of assistive devices during rehabilitation at BHC and found that they

contributed to participation in activities the children otherwise would not have participated in. The children highlighted "independence in activities" and "having the opportunity to participate in activities with family and friends" as important for frequent use. Willis et al. (196) tried to dig into the content of the rehabilitation for children carried out at BHC. They did so by describing the association between context, mechanisms and outcomes of the intervention in order to understand what works, in what conditions, and how. Findings indicate that the mechanisms choice, fun, friends, specialized health professionals, and time were activated in a context that was safe, social, learning-based and family-centered, to elicit outcomes across all levels of the ICF. The latter suggesting that the participation-focused approach may act as a catalyst to promote a range of outcomes.

## Clinical relevance

The clinical relevance of improvement in physical and particularly in mental functioning can be questioned. Minimal clinically important difference (MCID) may vary across conditions and settings (136, 197). For the RCT, when applying an MCID of four points (198), approximately half of the subjects were expected to have a clinically relevant improvement. The magnitude of improvement in both mental and physical functioning was also similar across the three disability groups. Although the SF-12 is a generic measurement, the clinical significance of changes may vary across disabilities and be influenced by environmental factors. Large variations have been reported in the literature (199-202). Because of the detected change, the improvement in mental and physical functioning from baseline to discharge in this study is of high clinical relevance.

For long-term outcome on functioning, improvements in both mental and physical functioning were just below the levels of clinical relevance (2.88 and 1.99, respectively) when comparing to a previous study that reports detectable changes of 3 for MCS and 2-3 for PCS (203).

The study carried out in the present thesis, especially the goal-setting part, is close to a pragmatic trial. We are studying what actually happens in the clinical setting at the rehabilitation facility, displaying what works, but also exposing challenges and problems. The strength of the pragmatic approach is that it has a very high clinical relevance. The weakness lays in issues with internal validity, when studying what happens, you might not really get the essence of what is going on.

# CONCLUSION AND SCIENTIFIC IMPACT

The work of the present thesis seeks to evaluate the short- and long-term effects of adapted physical activity-based rehabilitation on mental and physical functioning for subjects with chronic disabilities. Results indicate that the four-week intervention improved both short- and long-term mental and physical functioning. The thesis also seeks to detect possible predictors influencing outcome on functioning. Results reveals that short-term improvement in functioning was related to improved self-efficacy for social and recreational activities, while subjects having a low self-efficacy for managing chronic disease and high levels of fatigue at baseline seemed to benefit the most regarding long-term improvement of functioning. The subjects listed a high goal achievement, and goal achievement was positively correlated with long-term improvement in mental functioning. Last, the thesis seeks to identify the content of goals set among individuals attending rehabilitation and compare them to negotiated goals set in collaboration with the rehabilitation team. Results indicate that Body Functions-goals were most frequent. Goal negotiation resulted in a higher frequency of Activity and participation-goals and better specified goals. Health professionals captured the content of the individual goals to a great extent.

This thesis studies elements of the rehabilitation process bringing new knowledge to the field regarding physical activity for people with disabilities. That we were able to study outcome by carrying out an RCT and to study the goal-setting processes in detail, might bring us closer to understand what is going on in the black box of rehabilitation and in measuring the participation construct. Very few studies have evaluated the effects of an APA-based intervention. This study contributes important knowledge about APA-based interventions in a generalized group of subjects with chronic disabilities.

# FUTURE PERSPECTIVES

Even though the thesis has a long-term follow-up after rehabilitation, there is a need for further research on long-term effects and over even longer time periods. Emphasis should also be put on reducing the observed decrease in mental and physical functioning after discharge and on factors in the local environment contributing to sustained functioning. This thesis studies the goal-setting process “as is”. In order to gain knowledge of factors contributing to both improvement in and sustained functioning, as well as goal-setting as an ingredient in rehabilitation, future research must try to dig deeper into the black box.

# REFERENCES


1. Roe C, Preede L, Dalen H, Bautz-Holter E, Nyquist A, Sandvik L, et al. Does adapted physical activity-based rehabilitation improve mental and physical functioning? A randomized trial. Eur J Phys Rehabil Med. 2016.
2. Preede L, Saebu M, Perrin PB, Nyquist A, Dalen H, Bautz-Holter E, et al. One-year trajectories of mental and physical functioning during and after rehabilitation among individuals with disabilities. Health and quality of life outcomes. 2015;13:135.
3. Reed G. Beitostolen: Shangri-la for the Handicapped. The Physician and Sportsmedicine. 1978;6(11):146-50.
4. Cieza A. Rehabilitation the Health Strategy of the 21st Century, Really? Arch Phys Med Rehabil. 2019;100(11):2212-4.
5. Solvang PK. (Re)habilitering : terapi, tilrettelegging, verdsetting. 1. utgave. ed. Bergen: Fagbokforlaget; 2019.
6. World Health Organization. World report on disability 2011 [Available from: http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1.
7. Statistisk Sentralbyrå. Funksjonshemmede, arbeidskraftundersøkelsen, 2019, 2. kvartal 2019 [cited 2019 20.09.19]. Available from: https://www.ssb.no/arbeid-og-lonn/statistikker/akutu.
8. Silvers A. A fatal attraction to normalizing. In: Parens, editor. Enhancing human traits. Washington DC: Georgetown University Press; 1998.
9. Hammel KW. Perspectives on Disability and Rehabilitation. Contesting Assumptions, Challenging Practice. Toronto: Churchill Livingstone Elsevier; 2006.
10. UNION OPIAS. Fundamental principles of disability. London: UPIAS. 1975.
11. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization,; 2001.
12. Shakespeare T. Social models of disability and other life strategies. Scandinavian Journal of Disability Research. 2004;6(1):8-21.
13. Gustavsson A. The role of theory in disability research ‐ springboard or strait ‐ jacket? Scandinavian Journal of Disability Research. 2004;6(1):55-70.
14. Gustavsson A. Resistance, Reflection and Change: Nordic Disability Research: Studentlitteratur; 2005.
15. Sosial- og helsedepartementet. St.meld. nr. 8 (1998-99) Om handlingsplan for funksjonshemma 1998-2001 1998 [Available from: https://www.regjeringen.no/no/dokumenter/stmeld-nr-8-1998-99-/id430886/sec2?q=funksjonshemming.
16. Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. National Institutional Frameworks and Human Rights of Persons with Disabilities. Background conference document. United Nations General Assembly 2006 [Available from: http://www.un.org/esa/socdev/enable/rights/ahc8documents.htm.
17. Merskey H, Albe-Fessard D, Bonica J, Carmon A, Dubner R, Kerr F, et al. Pain terms: a list with definitions and notes on usage. Recommended by the IASP Subcommittee on Taxonomy. Pain. 1979;6(3):249.
18. Merskey H, Bogduk N. Classification of chronic pain, Part III: Pain terms, a current list with definitions and notes on usage. IASP task force on taxonomy. Seattle: IASP Press; 1994. 209-14 p.
19. Chandratre P, Roddy E, Clarson L, Richardson J, Hider SL, Mallen CD. Health-related quality of life in gout: a systematic review. Rheumatology (Oxford). 2013;52(11):2031-40.
20. Stalnacke BM. Life satisfaction in patients with chronic pain - relation to pain intensity, disability, and psychological factors. Neuropsychiatr Dis Treat. 2011;7:683-9.
21. Fine PG. Long-term consequences of chronic pain: mounting evidence for pain as a neurological disease and parallels with other chronic disease states. Pain Med. 2011;12(7):996-1004.
22. Hallstam A, Lofgren M, Svensen C, Stalnacke BM. Patients with chronic pain: One-year follow-up of a multimodal rehabilitation programme at a pain clinic. Scand J Pain. 2016;10:36-42.
23. Rombaut L, Malfait F, Cools A, De Paepe A, Calders P. Musculoskeletal complaints, physical activity and health-related quality of life among patients with the Ehlers-Danlos syndrome hypermobility type. Disabil Rehabil. 2010;32(16):1339-45.
24. Dobkin BH. Fatigue versus activity-dependent fatigability in patients with central or peripheral motor impairments. Neurorehabil Neural Repair. 2008;22(2):105-10.
25. Brunton LK, McPhee PG, Gorter JW. Self-reported factors contributing to fatigue and its management in adolescents and adults with cerebral palsy. Disabil Rehabil. 2019:1-7.
26. Kemp B, Thompson L. Aging and spinal cord injury: medical, functional, and psychosocial changes. SCI Nurs. 2002;19(2):51-60.

27. Ochs LA, Roessler RT. Students with Disabilities:How Ready Are They for the 21st Century? Rehabilitation Counseling Bulletin. 2001;44(3):170-6.
28. Cairney J, Hay JA, Faught BE, Wade TJ, Corna L, Flouris A. Developmental Coordination Disorder, Generalized Self-Efficacy Toward Physical Activity, and Participation in Organized and Free Play Activities. The Journal of Pediatrics. 2005;147(4):515-20.
29. Saebu M, Sorensen M. Factors associated with physical activity among young adults with a disability. ScandJMedSciSports. 2011;21(5):730-8.
30. King ACB, Steven N.; Bild, Diane E.; Dishman, Rod K.; Dubbert, Patricia M.; Marcus, Bess H.; Oldridge, Neil B.; Paffenbarger, Ralph S.; Powell, Kenneth E.; Yeager, Kim K. Determinants of physical activity and interventions in adults. Med Sci Sports Exerc. 1992;Vol 24(6, Suppl).
31. Sorensen M. Motivation for physical activity of psychiatric patients when physical activity was offered as part of treatment. Scand J Med Sci Sports. 2006;16(6):391-8.
32. Kosma M, Ellis R, Cardinal BJ, Bauer JJ, McCubbin JA. Psychosocial predictors of physical activity and health-related quality of life among adults with physical disabilities: an integrative framework. Disabil Health J. 2009;2(2):104-9.
33. Saebu M, Sorensen M, Halvari H. Motivation for physical activity in young adults with physical disabilities during a rehabilitation stay: a longitudinal test of self-determination theory. J Appl Soc Psychol. 2013;43(3):612-25.
34. Bandura A. Social foundations of thought and action: A social cognitive theory. Englewood Cliffs, NJ, US: Prentice-Hall, Inc; 1986. xiii, 617-xiii, p.
35. Bandura A. Health promotion by social cognitive means. Health Educ Behav. 2004;31(2):143-64.
36. Boslaugh SE, Andresen EM. Correlates of physical activity for adults with disability. Prev Chronic Dis. 2006;3(3):A78.
37. Bickenbach JE, Chatterji S, Badley EM, Ustun TB. Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. Soc Sci Med. 1999;48(9):1173-87.
38. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, et al. Linking health-status measurements to the international classification of functioning, disability and health. J Rehabil Med. 2002;34(5):205-10.
39. Alford VM, Ewen S, Webb GR, McGinley J, Brookes A, Remedios LJ. The use of the International Classification of Functioning, Disability and Health to understand the health and functioning experiences of people with chronic conditions from the person perspective: a systematic review. Disabil Rehabil. 2015;37(8):655-66.
40. Soberg HL, Sandvik L, Ostensjo S. Reliability and applicability of the ICF in coding problems, resources and goals of persons with multiple injuries. Disabil Rehabil. 2008;30(2):98-106.
41. Stucki G, Cieza A, Melvin J. The International Classification of Functioning, Disability and Health (ICF): a unifying model for the conceptual description of the rehabilitation strategy. J Rehabil Med. 2007;39(4):279-85.
42. Stucki G, Bickenbach J, Melvin J. Strengthening Rehabilitation in Health Systems Worldwide by Integrating Information on Functioning in National Health Information Systems. Am J Phys Med Rehabil. 2017;96(9):677-81.
43. The American Academy of Orthotists & Prosthetists. Online Learning Center [Available from: http://www.oandp.org/olc/lessons/html/SSC_09/module2.asp?frmCourseSectionId=7CC1D52A-9E9D-4A03-A2F0-78AE7DB64977.
44. United Nations. United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 26 – Habilitation and rehabilitation 2006 [Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-26-habilitation-and-rehabilitation.html.
45. Helse- og omsorgsdepartementet. Forskrift om habilitering og rehabilitering, individuell plan og koordinator, Kapittel 2. Generelt om habilitering og rehabilitering § 3.Definisjon av habilitering og rehabilitering 2011 [
46. Stucki G, Stier-Jarmer M, Grill E, Melvin J. Rationale and principles of early rehabilitation care after an acute injury or illness. Disabil Rehabil. 2005;27(7-8):353-9.
47. Andelic N, Bautz-Holter E, Ronning P, Olafsen K, Sigurdardottir S, Schanke AK, et al. Does an early onset and continuous chain of rehabilitation improve the long-term functional outcome of patients with severe traumatic brain injury? J Neurotrauma. 2012;29(1):66-74.
48. Indredavik B, Bakke F, Slordahl SA, Rokseth R, Haheim LL. Treatment in a combined acute and rehabilitation stroke unit: which aspects are most important? Stroke. 1999;30(5):917-23.
49. Carlson JE, Zocchi KA, Bettencourt DM, Gambrel ML, Freeman JL, Zhang D, et al. Measuring frailty in the hospitalized elderly: concept of functional homeostasis. Am J Phys Med Rehabil. 1998;77(3):252-7.

50. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Deveoping and evaluating complex interventions: new guidance2006.
51. Dijkers MP. Rehabilitation treatment taxonomy: establishing common ground. Arch Phys Med Rehabil. 2014;95(1 Suppl):S1-5 e2.
52. Wade DT. Research into the black box of rehabilitation: the risks of a Type III error. Clin Rehabil. 2001;15(1):1-4.
53. Keith RA. Treatment strength in rehabilitation. Arch Phys Med Rehabil. 1997;78(12):1298-304.
54. Whyte J. A grand unified theory of rehabilitation (we wish!). The 57th John Stanley Coulter Memorial Lecture. Arch Phys Med Rehabil. 2008;89(2):203-9.
55. Dijkers MP, Hart T, Tsaousides T, Whyte J, Zanca JM. Treatment taxonomy for rehabilitation: past, present, and prospects. Arch Phys Med Rehabil. 2014;95(1 Suppl):S6-16.
56. Whyte J, Dijkers MP, Hart T, Zanca JM, Packel A, Ferraro M, et al. Development of a theory-driven rehabilitation treatment taxonomy: conceptual issues. Arch Phys Med Rehabil. 2014;95(1 Suppl):S24-32 e2.
57. Whyte J. Contributions of treatment theory and enablement theory to rehabilitation research and practice. Arch Phys Med Rehabil. 2014;95(1 Suppl):S17-23 e2.
58. Dijkers MP, Ferraro MK, Hart T, Packel A, Whyte J, Zanca JM. Toward a rehabilitation treatment taxonomy: summary of work in progress. Phys Ther. 2014;94(3):319-21.
59. Hart T, Tsaousides T, Zanca JM, Whyte J, Packel A, Ferraro M, et al. Toward a theory-driven classification of rehabilitation treatments. Arch Phys Med Rehabil. 2014;95(1 Suppl):S33-44 e2.
60. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Rep. 1985;100(2):126-31.
61. Swift DL, McGee JE, Earnest CP, Carlisle E, Nygard M, Johannsen NM. The Effects of Exercise and Physical Activity on Weight Loss and Maintenance. Prog Cardiovasc Dis. 2018;61(2):206-13.
62. Ekblom-Bak E, Ekblom B, Vikström M, de Faire U, Hellénius M-L. The importance of non-exercise physical activity for cardiovascular health and longevity. Br J Sports Med. 2014;48(3):233-8.
63. Penedo FJ, Dahn JR. Exercise and well-being: a review of mental and physical health benefits associated with physical activity. Current Opinion in Psychiatry. 2005;18(2):189-93.
64. Deslandes A, Moraes H, Ferreira C, Veiga H, Silveira H, Mouta R, et al. Exercise and mental health: many reasons to move. Neuropsychobiology. 2009;59(4):191-8.
65. Tremblay MS, Aubert S, Barnes JD, Saunders TJ, Carson V, Latimer-Cheung AE, et al. Sedentary Behavior Research Network (SBRN) - Terminology Consensus Project process and outcome. Int J Behav Nutr Phys Act. 2017;14(1):75.
66. Hamilton MT, Hamilton DG, Zderic TW. Role of low energy expenditure and sitting in obesity, metabolic syndrome, type 2 diabetes, and cardiovascular disease. Diabetes. 2007;56(11):2655-67.
67. Patterson R, McNamara E, Tainio M, de Sá TH, Smith AD, Sharp SJ, et al. Sedentary behaviour and risk of all-cause, cardiovascular and cancer mortality, and incident type 2 diabetes: a systematic review and dose response meta-analysis. Eur J Epidemiol. 2018;33(9):811-29.
68. Anderson LS, Heyne LA. Physical activity for children and adults with disabilities: An issue of "amplified" importance. Disabil Health J. 2010;3(2):71-3.
69. Kinne S, Patrick DL, Doyle DL. Prevalence of secondary conditions among people with disabilities. Am J Public Health. 2004;94(3):443-5.
70. Bauman WA, Spungen AM, Adkins RH, Kemp BJ. Metabolic and endocrine changes in persons aging with spinal cord injury. Assist Technol. 1999;11(2):88-96.
71. Holmgren M, de Munter J, Rasmussen F, Sandberg M, Ahlström G. Is Obesity More Than a Double Burden among People with Mobility Disability? The Effect of Obesity on HRQoL and Participation in Society. Healthcare (Basel). 2017;5(4):79.
72. Fox KR. The influence of physical activity on mental well-being. Public Health Nutr. 1999;2(3A):411-8.
73. Martin JJ. Benefits and barriers to physical activity for individuals with disabilities: a social-relational model of disability perspective. Disabil Rehabil. 2013;35(24):2030-7.
74. Grue L. På terskelen. En undersøkelse av funksjonshemmet ungdoms sosiale tilhørighet, selvbilde og livskvalitet (On the threshold. An investigation of disabled youth's social attachments, self-concept and quality of life. 1998.
75. Ellis R, Kosma M, Cardinal BJ, Bauer JJ, McCubbin JA. Physical activity beliefs and behaviour of adults with physical disabilities. Disabil Rehabil. 2007;29(15):1222-8.
76. Jahnsen R VL, Aamodt G, Stanghelle JK, et al. Physiotherapy and physical activity - Experiences of adults with cerebral palsy with implications for children. Advances in Physiotherapy 5(1):21-32. 2003.
77. Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. J Rehabil Res Dev. 2008;45(2):315-22.

78. Scascighini L, Toma V, Dober-Spielmann S, Sprott H. Multidisciplinary treatment for chronic pain: a systematic review of interventions and outcomes. Rheumatology (Oxford). 2008;47(5):670-8.
79. Denison E, Asenlof P, Sandborgh M, Lindberg P. Musculoskeletal pain in primary health care: subgroups based on pain intensity, disability, self-efficacy, and fear-avoidance variables. J Pain. 2007;8(1):67-74.
80. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev. 1977;84(2):191-215.
81. Denison E, Asenlof P, Lindberg P. Self-efficacy, fear avoidance, and pain intensity as predictors of disability in subacute and chronic musculoskeletal pain patients in primary health care. Pain. 2004;111(3):245-52.
82. Engen G, Saebu M, Juritzen TI, Bliksvaer T, Engebretsen E, Soberg HL, et al. A Systematic Review of Rehabilitation Interventions Aimed at Improving Participation in Life Domains for Young Adults with Disabilities. Int J Phys Med Rehabil 2016;4(1):-.
83. Johansen OM, G; Morisbak, I; Rotevatn, L. Beitostølen Helsesportsenter 1970-1995, 25-års jubileumsskrift: Beitostølen Helsesportsenter; 1995.
84. Hutzler Y, Sherrill C. Defining adapted physical activity: international perspectives. Adapted physical activity quarterly : APAQ. 2007;24(1):1-20.
85. Kersten P, Ellis-Hill C, McPherson KM, Harrington R. Beyond the RCT - understanding the relationship between interventions, individuals and outcome - the example of neurological rehabilitation. Disabil Rehabil. 2010;32(12):1028-34.
86. Gardner T, Refshauge K, McAuley J, Hübscher M, Goodall S, Smith L. Combined education and patient-led goal setting intervention reduced chronic low back pain disability and intensity at 12 months: a randomised controlled trial. Br J Sports Med. 2019;53(22):1424-31.
87. Playford ED, Siegert R, Levack W, Freeman J. Areas of consensus and controversy about goal setting in rehabilitation: a conference report. Clin Rehabil. 2009;23(4):334-44.
88. Levack WM, Dean SG, Siegert RJ, McPherson KM. Purposes and mechanisms of goal planning in rehabilitation: the need for a critical distinction. Disabil Rehabil. 2006;28(12):741-9.
89. Turner-Stokes L, Rose H, Ashford S, Singer B. Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation. International Journal of Therapy & Rehabilitation. 2015;22(5).
90. Locke EA, Latham GP. Building a practically useful theory of goal setting and task motivation. A 35-year odyssey. Am Psychol. 2002;57(9):705-17.
91. Locke EA, Latham GP. New Directions in Goal-Setting Theory. Curr Dir Psychol Sci. 2006;15(5):265-8.
92. Wade DT. Evidence relating to goal planning in rehabilitation. Clin Rehabil. 1998;12(4):273-5.
93. Wade DT. Goal setting in rehabilitation: an overview of what, why and how. Clin Rehabil. 2009;23(4):291-5.
94. Eftekhar P, Mochizuki G, Dutta T, Richardson D, Brooks D. Goal Attainment Scaling in Individuals with Upper Limb Spasticity Post Stroke. Occup Ther Int. 2016;23(4):379-89.
95. Nguyen L, Cross A, Rosenbaum P, Gorter JW. Use of the International Classification of Functioning, Disability and Health to support goal-setting practices in pediatric rehabilitation: a rapid review of the literature. Disabil Rehabil. 2019:1-11.
96. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G. ICF linking rules: an update based on lessons learned. J Rehabil Med. 2005;37(4):212-8.
97. Dager TN, Kjeken I, Berdal G, Sand-Svartrud AL, Bo I, Dingsor A, et al. Rehabilitation for patients with rheumatic diseases: Patient experiences of a structured goal planning and tailored follow-up programme. SAGE Open Med. 2017;5:2050312117739786.
98. Wade DT, de Jong BA. Recent advances in rehabilitation. BMJ. 2000;320(7246):1385-8.
99. Siegert RJ, McPherson KM, Taylor WJ. Toward a cognitive-affective model of goal-setting in rehabilitation: is self-regulation theory a key step? Disabil Rehabil. 2004;26(20):1175-83.
100. McAndrew E, McDermott S, Vitzakovitch S, Warunek M, Holm MB. Therapist and Patient Perceptions of the Occupational Therapy Goal-Setting Process. Phys Occup Ther Geriatr. 2009;17(1):55-63.
101. Holliday RC, Cano S, Freeman JA, Playford ED. Should patients participate in clinical decision making? An optimised balance block design controlled study of goal setting in a rehabilitation unit. J Neurol Neurosurg Psychiatry. 2007;78(6):576-80.
102. Soberg HL, Finset A, Roise O, Bautz-Holter E. Identification and comparison of rehabilitation goals after multiple injuries: an ICF analysis of the patients', physiotherapists' and other allied professionals' reported goals. J Rehabil Med. 2008;40(5):340-6.
103. Liu KP, Chan CC, Chan F. Would discussion on patients' needs add value to the rehabilitation process? Int J Rehabil Res. 2005;28(1):1-7.

104. Leach E, Cornwell P, Fleming J, Haines T. Patient centered goal-setting in a subacute rehabilitation setting. Disabil Rehabil. 2010;32(2):159-72.
105. Glazier SR, Schuman J, Keltz E, Vally A, Glazier RH. Taking the next steps in goal ascertainment: a prospective study of patient, team, and family perspectives using a comprehensive standardized menu in a geriatric assessment and treatment unit. J Am Geriatr Soc. 2004;52(2):284-9.
106. Rice DB, McIntyre A, Mirkowski M, Janzen S, Viana R, Britt E, et al. Patient-Centered Goal Setting in a Hospital-Based Outpatient Stroke Rehabilitation Center. PM R. 2017;9(9):856-65.
107. Lohmann S, Decker J, Muller M, Strobl R, Grill E. The ICF forms a useful framework for classifying individual patient goals in post-acute rehabilitation. J Rehabil Med. 2011;43(2):151-5.
108. Haas B, Playford ED, Ahmad AQ, Yildiran T, Gibbon AJ, Freeman JA. Rehabilitation goals of people with spinal cord injuries can be classified against the International Classification of Functioning, Disability and Health Core Set for spinal cord injuries. Spinal Cord. 2016;54(4):324-8.
109. Levack WM, Taylor K, Siegert RJ, Dean SG, McPherson KM, Weatherall M. Is goal planning in rehabilitation effective? A systematic review. Clin Rehabil. 2006;20(9):739-55.
110. Hurn J, Kneebone I, Cropley M. Goal setting as an outcome measure: A systematic review. Clin Rehabil. 2006;20(9):756-72.
111. Turner-Stokes L, Williams H, Johnson J. Goal attainment scaling: does it provide added value as a person-centred measure for evaluation of outcome in neurorehabilitation following acquired brain injury? J Rehabil Med. 2009;41(7):528-35.
112. Muller M, Strobl R, Grill E. Goals of patients with rehabilitation needs in acute hospitals: goal achivement is an indicator for improved functioning. J Rehabil Med. 2011;43(2):145-50.
113. Kus S, Muller M, Strobl R, Grill E. Patient goals in post-acute geriatric rehabilitation--goal attainment is an indicator for improved functioning. J Rehabil Med. 2011;43(2):156-61.
114. Hammel J, Jones R, Smith J, Sanford J, Bodine C, Johnson M. Environmental barriers and supports to the health, function, and participation of people with developmental and intellectual disabilities: report from the State of the Science in Aging with Developmental Disabilities Conference. Disabil Health J. 2008;1(3):143-9.
115. Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. Dev Med Child Neurol. 2017;59(1):16-25.
116. Willis C, Girdler S, Thompson M, Rosenberg M, Reid S, Elliott C. Elements contributing to meaningful participation for children and youth with disabilities: a scoping review. Disabil Rehabil. 2016:1-14.
117. Van de Velde D, Coorevits P, Sabbe L, De Baets S, Bracke P, Van Hove G, et al. Measuring participation as defined by the World Health Organization in the International Classification of Functioning, Disability and Health. Psychometric properties of the Ghent Participation Scale. Clin Rehabil. 2017;31(3):379-93.
118. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. Arch Phys Med Rehabil. 2010;91(9 Suppl):S5-16.
119. Granlund M. Participation – challenges in conceptualization, measurement and intervention. Child Care Health Dev. 2013;39(4):470-3.
120. Imms C, Adair B, Keen D, Ullenhag A, Rosenbaum P, Granlund M. 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. Dev Med Child Neurol. 2016;58(1):29-38.
121. Adair B, Ullenhag A, Keen D, Granlund M, Imms C. The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. Dev Med Child Neurol. 2015;57(12):1093-104.
122. Longo E, Badia M, Begona Orgaz M, Gomez-Vela M. Comparing parent and child reports of health-related quality of life and their relationship with leisure participation in children and adolescents with Cerebral Palsy. Res Dev Disabil. 2017;71:214-22.
123. Diaz R, Miller EK, Kraus E, Fredericson M. Impact of Adaptive Sports Participation on Quality of Life. Sports Med Arthrosc Rev. 2019;27(2):73-82.
124. Van De Velde D, Bracke P, Van Hove G, Josephsson S, Viaene A, De Boever E, et al. Measuring participation when combining subjective and objective variables: the development of the Ghent Participation Scale (GPS). Eur J Phys Rehabil Med. 2016;52(4):527-40.
125. Keller SD, Ware JE, Jr., Bentler PM, Aaronson NK, Alonso J, Apolone G, et al. Use of structural equation modeling to test the construct validity of the SF-36 Health Survey in ten countries: results from the IQOLA Project. International Quality of Life Assessment. J Clin Epidemiol. 1998;51(11):1179-88.
126. Chapman JR, Norvell DC, Hermsmeyer JT, Bransford RJ, DeVine J, McGirt MJ, et al. Evaluating common outcomes for measuring treatment success for chronic low back pain. Spine (Phila Pa 1976). 2011;36(21 Suppl):S54-68.

127. Chen P, Lin KC, Liing RJ, Wu CY, Chen CL, Chang KC. Validity, responsiveness, and minimal clinically important difference of EQ-5D-5L in stroke patients undergoing rehabilitation. Qual Life Res. 2016;25(6):1585-96.
128. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992;30(6):473-83.
129. Maruf FA, Akinpelu AO, Salako BL. Self-reported quality of life before and after aerobic exercise training in individuals with hypertension: a randomised-controlled trial. Applied psychology Health and well-being. 2013;5(2):209-24.
130. Smart NA, Murison R. Rate of change in physical fitness and quality of life and depression following exercise training in patients with congestive heart failure. Congest Heart Fail. 2013;19(1):1-5.
131. Lauret GJ, van Dalen DC, Willigendael EM, Hendriks EJ, de Bie RA, Spronk S, et al. Supervised exercise therapy for intermittent claudication: current status and future perspectives. Vascular. 2012;20(1):12-9.
132. Cugusi L, Solla P, Zedda F, Loi M, Serpe R, Cannas A, et al. Effects of an adapted physical activity program on motor and non-motor functions and quality of life in patients with Parkinson's disease. NeuroRehabilitation. 2014;35(4):789-94.
133. Taricco M, Dallolio L, Calugi S, Rucci P, Fugazzaro S, Stuart M, et al. Impact of adapted physical activity and therapeutic patient education on functioning and quality of life in patients with postacute strokes. Neurorehabil Neural Repair. 2014;28(8):719-28.
134. Beitostølen Helsesportsenter. Beitostølen Healthsports Center 2016 [Available from: http://bhss.no/om-senteret/beitostoelen-healthsports-center/.
135. Ware J, Jr., Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care. 1996;34(3):220-33.
136. Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. How to Score Version 2 of the SF-12(R) Health Survey. Lincoln, RI: QualityMetric Incorporated; 2002 2002.
137. Gandek B, Ware JE, Aaronson NK, Apolone G, Bjorner JB, Brazier JE, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. J Clin Epidemiol. 1998;51(11):1171-8.
138. Turner-Bowker DM, Bayliss MS, Ware JE, Jr., Kosinski M. Usefulness of the SF-8 Health Survey for comparing the impact of migraine and other conditions. Qual Life Res. 2003;12(8):1003-12.
139. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract. 2001;4(6):256-62.
140. Lorig K, Stewart A, Ritter P, González V, Laurent D, Lynch J. Outcome Measures for Health Education and other Health Care Interventions: Thousand Oaks CA: Sage Publications; 1996 1/1/1996.
141. Riehm KE, Kwakkenbos L, Carrier M-E, Bartlett SJ, Malcarne VL, Mouthon L, et al. Validation of the Self-Efficacy for Managing Chronic Disease Scale: A Scleroderma Patient-Centered Intervention Network Cohort Study. Arthritis Care Res (Hoboken). 2016;68(8):1195-200.
142. Wolfe F. Fatigue assessments in rheumatoid arthritis: comparative performance of visual analog scales and longer fatigue questionnaires in 7760 patients. J Rheumatol. 2004;31(10):1896-902.
143. Huskisson EC. Measurement of pain. Lancet. 1974;2(7889):1127-31.
144. Markland D TV. A modification to the behavioural regulation in exercise questionnaires to include an assessent of a motivation. J Sport Exerc Psychol. 2004:191-6.
145. Thogersen-Ntoumani C, Ntoumanis N. The role of self-determined motivation in the understanding of exercise-related behaviours, cognitions and physical self-evaluations. J Sports Sci. 2006;24(4):393-404.
146. Riiser K, Ommundsen Y, Smastuen MC, Londal K, Misvaer N, Helseth S. The relationship between fitness and health-related quality of life and the mediating role of self-determined motivation in overweight adolescents. Scand J Public Health. 2014;42(8):766-72.
147. Roe C, Dalen H, Lein M, Bautz-Holter E. Comprehensive rehabilitation at Beitostolen Healthsports Centre: influence on mental and physical functioning. J Rehabil Med. 2008;40(6):410-7.
148. Blaasvaer S, Stanghelle JK. Rehabilitation with proper physical activities - what happens with patients' quality of life? TidsskrNor Laegeforen. 1999;119(9):1281-6.
149. Cartwright N. Are RCTs the Gold Standard? BioSocieties. 2007;2(1):11-20.
150. Grossman J, Mackenzie FJ. The randomized controlled trial: gold standard, or merely standard? Perspect Biol Med. 2005;48(4):516-34.
151. Cicerone KD, Azulay J, Trott C. Methodological quality of research on cognitive rehabilitation after traumatic brain injury. Arch Phys Med Rehabil. 2009;90(11 Suppl):S52-9.
152. Jones R, Jones RO, McCowan C, Montgomery AA, Fahey T. The external validity of published randomized controlled trials in primary care. BMC Fam Pract. 2009;10:5.
153. Kennedy-Martin T, Curtis S, Faries D, Robinson S, Johnston J. A literature review on the representativeness of randomized controlled trial samples and implications for the external validity of trial results. Trials. 2015;16(1):495.

154. Rothwell PM. Factors that can affect the external validity of randomised controlled trials. PLoS Clin Trials. 2006;1.
155. Torgerson DJ, Roland M. What is Zelen's design? BMJ : British Medical Journal. 1998;316(7131):606-.
156. Rothwell PM. External validity of randomised controlled trials: "to whom do the results of this trial apply?". Lancet. 2005;365(9453):82-93.
157. Viera AJ, Bangdiwala SI. Eliminating bias in randomized controlled trials: importance of allocation concealment and masking. Fam Med. 2007;39(2):132-7.
158. OECD. Education at a Glance 20202020.
159. Bufdir. Høyere utdanning: Barne-, ungdoms- og familiedirektoratet; 2020 [Available from: https://bufdir.no/Statistikk_og_analyse/Nedsatt_funksjonsevne/Oppvekst_og_utdanning/Hoyere_utdanning/#heading6927.
160. Farivar SS, Cunningham WE, Hays RD. Correlated physical and mental health summary scores for the SF-36 and SF-12 Health Survey, V.I. Health and quality of life outcomes. 2007;5:54.
161. Hopman WM, Harrison MB, Coo H, Friedberg E, Buchanan M, VanDenKerkhof EG. Associations between chronic disease, age and physical and mental health status. Chronic Dis Can. 2009;29(3):108-16.
162. Whynes DK, McCahon RA, Ravenscroft A, Hodgkinson V, Evley R, Hardman JG. Responsiveness of the EQ-5D health-related quality-of-life instrument in assessing low back pain. Value Health. 2013;16(1):124-32.
163. Khanna D, Tsevat J. Health-related quality of life--an introduction. Am J Manag Care. 2007;13 Suppl 9:S218-23.
164. Lou J-S. Physical and Mental Fatigue in Parkinson's Disease. Drugs Aging. 2009;26(3):195-208.
165. Willis C, Nyquist A, Jahnsen R, Elliott C, Ullenhag A. Enabling physical activity participation for children and youth with disabilities following a goal-directed, family-centred intervention. Res Dev Disabil. 2018;77:30-9.
166. McCullagh R, Fitzgerald AP, Murphy RP, Cooke G. Long-term benefits of exercising on quality of life and fatigue in multiple sclerosis patients with mild disability: a pilot study. Clin Rehabil. 2008;22(3):206-14.
167. Roine E, Roine RP, Rasanen P, Vuori I, Sintonen H, Saarto T. Cost-effectiveness of interventions based on physical exercise in the treatment of various diseases: a systematic literature review. Int J Technol Assess Health Care. 2009;25(4):427-54.
168. Motl RW, McAuley E. Longitudinal Analysis of Physical Activity and Symptoms as Predictors of Change in Functional Limitations and Disability in Multiple Sclerosis. Rehabil Psychol. 2009;54(2):204-10.
169. Tallner A, Waschbisch A, Hentschke C, Pfeifer K, Maurer M. Mental Health in Multiple Sclerosis Patients without Limitation of Physical Function: The Role of Physical Activity. Int J Mol Sci. 2015;16(7):14901-11.
170. Stuifbergen AK, Blozis SA, Harrison TC, Becker HA. Exercise, functional limitations, and quality of life: A longitudinal study of persons with multiple sclerosis. Arch Phys Med Rehabil. 2006;87(7):935-43.
171. Latimer AE, Ginis KAM, Arbour KP. The efficacy of an implementation intention intervention for promoting physical activity among individuals with spinal cord injury: A randomized controlled trial. Rehabil Psychol. 2006;51(4):273-80.
172. Boosman H, Visser-Meily JM, Meijer JW, Elsinga A, Post MW. Evaluation of change in fatigue, self-efficacy and health-related quality of life, after a group educational intervention programme for persons with neuromuscular diseases or multiple sclerosis: a pilot study. Disabil Rehabil. 2011;33(8):690-6.
173. Staniute M, Bunevicius A, Brozaitiene J, Bunevicius R. Relationship of health-related quality of life with fatigue and exercise capacity in patients with coronary artery disease. Eur J Cardiovasc Nurs. 2014;13(4):338-44.
174. Tersteeg IM, Koopman FS, Stolwijk-Swuste JM, Beelen A, Nollet F, Group CS. A 5-year longitudinal study of fatigue in patients with late-onset sequelae of poliomyelitis. Arch Phys Med Rehabil. 2011;92(6):899-904.
175. Brusse E, Brusse-Keizer MG, Duivenvoorden HJ, van Swieten JC. Fatigue in spinocerebellar ataxia: patient self-assessment of an early and disabling symptom. Neurology. 2011;76(11):953-9.
176. Turpin KV, Carroll LJ, Cassidy JD, Hader WJ. Deterioration in the health-related quality of life of persons with multiple sclerosis: the possible warning signs. Mult Scler. 2007;13(8):1038-45.
177. Brock K, Black S, Cotton S, Kennedy G, Wilson S, Sutton E. Goal achievement in the six months after inpatient rehabilitation for stroke. Disabil Rehabil. 2009;31(11):880-6.
178. Hazard RG, Spratt KF, McDonough CM, Carayannopoulos AG, Olson CM, Reeves V, et al. The impact of personal functional goal achievement on patient satisfaction with progress one year following completion of a functional restoration program for chronic disabling spinal disorders. Spine (Phila Pa 1976). 2009;34(25):2797-802.

179. Coffey L, Gallagher P, Desmond D. Goal pursuit and goal adjustment as predictors of disability and quality of life among individuals with a lower limb amputation: a prospective study. Arch Phys Med Rehabil. 2014;95(2):244-52.
180. Church AT, Katigbak M, Locke K, Zhang H, Shen J, Vargas Flores JdJ, et al. Need Satisfaction and Well-Being. J Cross Cult Psychol. 2013;44:507-34.
181. Sæbu M. Physical activity and motivation in young adults with a physical disability [PhD thesis]. Oslo: Norwegian School of Sport Sciences 2011.
182. Rijken M, van Kerkhof M, Dekker J, Schellevis FG. Comorbidity of chronic diseases: effects of disease pairs on physical and mental functioning. Qual Life Res. 2005;14(1):45-55.
183. Hays RD, Wells KB, Sherbourne CD, Rogers W, Spritzer K. Functioning and well-being outcomes of patients with depression compared with chronic general medical illnesses. Arch Gen Psychiatry. 1995;52(1):11-9.
184. van der Slot WM, Nieuwenhuijsen C, van den Berg-Emons RJ, Wensink-Boonstra AE, Stam HJ, Roebroeck ME, et al. Participation and health-related quality of life in adults with spastic bilateral cerebral palsy and the role of self-efficacy. J Rehabil Med. 2010;42(6):528-35.
185. Redfors YD, Olaison S, Karlsson J, Hellgren J, Moller C. Hearing-related, health-related quality of life in patients who have undergone otosclerosis surgery: a long-term follow-up study. Int J Audiol. 2015;54(2):63-9.
186. Uhlig T, Loge JH, Kristiansen IS, Kvien TK. Quantification of reduced health-related quality of life in patients with rheumatoid arthritis compared to the general population. J Rheumatol. 2007;34(6):1241-7.
187. Casetta I, Riise T, Wamme Nortvedt M, Economou NT, De Gennaro R, Fazio P, et al. Gender differences in health-related quality of life in multiple sclerosis. Mult Scler. 2009;15(11):1339-46.
188. Benzer JK, Creech SK, Mohr DC, Charns MP. Learning goals may prevent "goals gone wild". Am J Public Health. 2014;104(12):e1.
189. Wressle E, Oberg B, Henriksson C. The rehabilitation process for the geriatric stroke patient--an exploratory study of goal setting and interventions. Disabil Rehabil. 1999;21(2):80-7.
190. Constand MK, MacDermid JC. Applications of the International Classification of Functioning, Disability and Health in goal-setting practices in healthcare. Disabil Rehabil. 2014;36(15):1305-14.
191. Wade DT. Research into rehabilitation. What is the priority? Clin Rehabil. 2001;15(3):229-32.
192. Shields N, Synnot AJ, Barr M. Perceived barriers and facilitators to physical activity for children with disability: a systematic review. Br J Sports Med. 2012;46(14):989-97.
193. Nyquist A, Jahnsen RB, Moser T, Ullenhag A. The coolest I know - a qualitative study exploring the participation experiences of children with disabilities in an adapted physical activities program. Disabil Rehabil. 2019:1-9.
194. Baksjoberget PE, Nyquist A, Moser T, Jahnsen R. Having Fun and Staying Active! Children with Disabilities and Participation in Physical Activity: A Follow-Up Study. Phys Occup Ther Pediatr. 2017;37(4):347-58.
195. Gjessing B, Jahnsen RB, Strand LI, Natvik E. Adaptation for participation! Disabil Rehabil Assist Technol. 2018;13(8):803-8.
196. Willis CE, Reid S, Elliott C, Rosenberg M, Nyquist A, Jahnsen R, et al. A realist evaluation of a physical activity participation intervention for children and youth with disabilities: what works, for whom, in what circumstances, and how? BMC Pediatr. 2018;18(1):113.
197. Garratt AM, Ruta DA, Abdalla MI, Buckingham JK, Russell IT. The SF36 health survey questionnaire: an outcome measure suitable for routine use within the NHS? BMJ. 1993;306(6890):1440-4.
198. Carreon LY, Glassman SD, Campbell MJ, Anderson PA. Neck Disability Index, short form-36 physical component summary, and pain scales for neck and arm pain: the minimum clinically important difference and substantial clinical benefit after cervical spine fusion. Spine J. 2010;10(6):469-74.
199. Warkentin LM, Majumdar SR, Johnson JA, Agborsangaya CB, Rueda-Clausen CF, Sharma AM, et al. Weight loss required by the severely obese to achieve clinically important differences in health-related quality of life: two-year prospective cohort study. BMC Med. 2014;12(1):175.
200. Wiebe S, Matijevic S, Eliasziw M, Derry PA. Clinically important change in quality of life in epilepsy. J Neurol Neurosurg Psychiatry. 2002;73(2):116-20.
201. Lauche R, Langhorst J, Dobos GJ, Cramer H. Clinically meaningful differences in pain, disability and quality of life for chronic nonspecific neck pain - a reanalysis of 4 randomized controlled trials of cupping therapy. Complement Ther Med. 2013;21(4):342-7.
202. Auffinger B, Lam S, Shen J, Thaci B, Roitberg BZ. Usefulness of minimum clinically important difference for assessing patients with subaxial degenerative cervical spine disease: statistical versus substantial clinical benefit. Acta Neurochir (Wien). 2013;155(12):2345-54; discussion 55.
203. Ware JE, Kosinski M, Bjorner JB, Turner-Bowker DM, Gandek B, Maruish ME. User's manual for the SF-36v2 health survey. 2nd ed: Quality Metric; 2007.

# APPENDICES

## Questionnaires

### Effekt av opphold ved BHSS - del A

Id. nr: ☐☐☐☐

**Spørreskjema om helse, fysisk aktivitet og mestring blant voksne med funksjonshemming knyttet til et forsknings-prosjekt ved Beitostølen Helsesportsenter. Vær vennlig å besvare skjema så raskt som mulig, og helst innen 3 dager.**

**DIN HELSE OG TRIVSEL**

**Denne delen av spørreskjemaet handler om hvordan du ser på din egen helse. Disse opplysningene vil hjelpe oss til å få vite hvordan du har det og hvordan du er i stand til å utføre dine daglige gjøremål.**
**For hvert av de følgende spørsmålene vennligst sett et ☒ i den ene luken som best beskriver ditt svar.**

1. Stort sett, vil du si at din helse er: Utmerket ☐ Meget god ☐ God ☐ Nokså god ☐ Dårlig ☐

De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er din helse slik at den begrenser deg i utførelsen av disse aktivitetene? Hvis ja, hvor mye?

| | Ja, begrenser meg mye | Ja, begrenser meg litt | Nei, begrenser meg ikke i det hele tatt |
|---|---|---|---|
| 2. Moderate aktiviteter som å flytte et bord, støvsuge, gå en tur eller drive med hagearbeid | ☐ | ☐ | ☐ |
| 3. Gå opp trappen flere etasjer | ☐ | ☐ | ☐ |

I løpet av løpet av de siste 4 ukene, har du hatt noen av de følgende problemer i ditt arbeid eller i andre av dine daglige gjøremål på grunn av din fysiske helse?

| | Hele tiden | Mye av tiden | En del av tiden | Litt av tiden | Ikke i det hele tatt |
|---|---|---|---|---|---|
| 4. Du har utrettet mindre enn du hadde ønsket | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. Du har vært hindret i å utføre visse typer arbeid eller gjøremål | ☐ | ☐ | ☐ | ☐ | ☐ |

**I løpet av de siste 4 ukene, har du hatt noen av de følgende problemer i ditt arbeid eller i andre av dine daglige gjøremål på grunn av følelsesmessige problemer som f.eks. å være deprimert eller engstelig?**

| | Hele tiden | Mye av tiden | En del av tiden | Litt av tiden | Ikke i det hele tatt |
|---|---|---|---|---|---|
| 6. Du har utrettet mindre enn du hadde ønsket | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. Du har utført arbeidet eller andre gjøremål mindre grundig enn vanlig | ☐ | ☐ | ☐ | ☐ | ☐ |

8. løpet av de siste 4 ukene, hvor mye har smerter påvirket ditt vanlige arbeid gjelder både arbeid utenfor hjemmet og husarbeid?

Ikke i det hele tatt ☐ Litt ☐ En del ☐ Mye ☐ Svært mye ☐

**De neste spørsmålene handler om hvordan du har følt deg og hvordan du her hatt det de siste 4 ukene. For hvert spørsmål, vennligst velg det svaralternativet som best beskriver hvordan du her hatt det. Hvor ofte i løpet av de siste 4 ukene har du:**

| | Hele tiden | Mye av tiden | En del av tiden | Litt av tiden | Ikke i det hele tatt |
|---|---|---|---|---|---|
| 9. Følt deg rolig og harmonisk? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10. Hatt mye overskudd? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11. Følt deg nedfor og deprimert? | ☐ | ☐ | ☐ | ☐ | ☐ |

12. løpet av de siste 4 ukene, hvor mye av tiden har din fysiske helse eller følelsesmessige problemer påvirket din sosiale omgang (som det å besøke venner, slektninger osv.)?

Hele tiden ☐ Nesten hele tiden ☐ En del av tiden ☐ Litt av tiden ☐ Ikke i det tatt ☐

## OM MESTRING

**Vi vil gjerne vite hvor sikker du er på at du kan gjennomføre ulike aktiviteter. For hvert av de følgende spørsmålene, velg det alternativet som samsvarer best med hvor sikker du er på at du kan gjennomføre oppgavene regelmessig.**

| | Ikke sikker i det hele tatt | | | | | | | | | | Svært sikker |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Hvor sikker er du på at du kan gjøre enkle øvelser for muskelstyrke og bevelighet tre til fire ganger per uke (tøy og bøy, med vekter osv.)? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 2. Hvor sikker er du på at du kan gjøre lett kondisjonstrening som å rulle raskt i rullestol, gåing, svømming eller sykling tre til fire ganger hver uke? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 3. Hvor sikker er du på at du kan trene uten å gjøre symptomene værre? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| **4.** Hvor sikker er du på at du kan fortsette å gjøre dine hobbyer og andre fritidssysler? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 5. Hvor sikker er du på at du kan fortsette å gjøre de tingene du liker å gjøre med venner og familie (som sosiale aktiviteter og fritidssysler). | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 6. Hvor sikker er du på at tretthet forårsaket av din sykdom/funksjonshemming ikke kan hindre deg i å gjøre noen av de tingene du har lyst til? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 7. Hvor sikker er du på at fysisk ubehag eller smerte forårsaket av din sykdom/funksjonshemming ikke kan hindre deg i å gjøre ting du har lyst til? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 8. Hvor sikker er du på at følelsesmessige plager forårsaket av din sykdom/funksjonshemming ikke kan hindre deg i å gjøre ting du har lyst til? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 9. Hvor sikker er du på at andre symptomer eller helseproblemer forårsaket av din sykdom/funksjonshemming ikke kan hindre deg i å gjøre ting du har lyst til? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 10. Hvor sikker er du på at du kan gjennomføre de ulike tiltak og aktiviteter som trengs for å bidra til at du kan redusere ditt behov for å gå til lege/spesialist? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |
| 11. Hvor sikker er du på at du kan gjøre andre ting enn å ta medisiner for å bidra til at sykdom/funksjonshemming i mindre grad påvirker ditt daglige liv? | 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | 10 |

## OM MOTIVASJON

**V i er interessert i de underliggende årsaker til menneskers beslutning om å drive, eller ikke drive med trening/fysisk aktivitet. Ved bruk av skalaen nedenfor, vennligst merk av i hvilken grad de følgende 19 påstandene passer for deg ved å sette ett kryss for hver påstand. Det er ingen riktige eller gale svar. Vær vennlig å fylle ut denne selv om du ikke synes at du trener regelmessig eller er fysisk aktiv.**

| | Stemmer ikke for meg | | Stemmer noen ganger for meg | | Stemmer godt for meg |
|---|---|---|---|---|---|
| 1. Jeg trener fordi andre mennesker sier at jeg burde | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2. Jeg får dårlig samvittighet når jeg ikke trener | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3. Jeg verdsetter fordelene med trening | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4. Jeg trener fordi det er morsomt | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. Jeg forstår ikke hvorfor jeg burde trene | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6. Jeg deltar i trening fordi mine venner/familie /kjæreste sier jeg burde | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. Jeg føler meg skamfull når jeg går glipp av en treningsøkt | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8. Det er viktig for meg å trene regelmessig | ☐ | ☐ | ☐ | ☐ | ☐ |
| 9. Jeg forstår ikke hvorfor jeg skulle bry meg med å trene. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10. Jeg nyter treningsøktene mine | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11. Jeg trener fordi andre vil bli misfornøyd med meg dersom jeg ikke gjør det | ☐ | ☐ | ☐ | ☐ | ☐ |
| 12. Jeg ser ikke poenget med trening | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13. Jeg føler meg mislykket når jeg ikke har trent på en stund | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14. Jeg synes det er viktig å ta seg tid til å trene regelmessig | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15. Jeg synes trening er en lystbetont aktivitet | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16. Jeg føler meg presset av mine venner/familie til å trene | ☐ | ☐ | ☐ | ☐ | ☐ |
| 17. Jeg blir rastløs dersom jeg ikke trener regelmessig | ☐ | ☐ | ☐ | ☐ | ☐ |
| 18. Jeg opplever glede og tilfredsstillelse ved å delta i trening | ☐ | ☐ | ☐ | ☐ | ☐ |
| 19. Jeg synes trening er bortkastet tid | ☐ | ☐ | ☐ | ☐ | ☐ |

OM FYSISK AKTIVITET

**Instruksjoner:**
Spørreskjemaet handler om ditt nåværende nivå for fysisk aktivitet og trening. Husk at det ikke finnes gale eller riktige svar. Vi ønsker bare å kartlegge ditt nåværende aktivitetsnivå.

## Aktivitet på fritida

**1. Hvor ofte i løpet av de siste 7 dager har du drevet med stillesittende aktiviteter som å lese, se på TV, spille dataspill eller gjort håndarbeid?**

☐ Aldri (gå til spm. 2) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer per dag brukte du på disse stillesittende aktivitetene?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**2. Hvor ofte i løpet av de siste 7 dager har du gått eller kjørt/rullet rullestol utendørs, uten at dette er for å trene? For eksempel for å komme deg til arbeid eller skole, gå tur med hunden, for å handle eller andre ærend?**

☐ Aldri (gå til spm. 3) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på å gå eller rulle utendørs?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**3. Hvor ofte i løpet av de siste 7 dager har du drevet med lett fysisk aktivitet (for eksempel bowling, fiske, dart, biljard, boccia) eller fysioterapi (for eksempel tøyninger eller ståtrening) eller andre liknende aktiviteter?**

☐ Aldri (gå til spm. 4) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på lett fysisk aktivitet eller fysioterapi?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**4. Hvor ofte i løpet av de siste 7 dager har du drevet med middels anstrengende fysisk aktivitet som å spille golf, danse, rulle rullestol i moderat fart eller andre liknende aktiviteter?**

☐ Aldri (gå til spm. 5) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på middels anstrengende fysisk aktivitet?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**5. Hvor ofte i løpet av de siste 7 dager har du drevet med anstrengende fysiske aktivitet som å jogge, rulle eller pigge fort med rullestol, svømming, aerobics, sykling/armsykling, tennis, basketball, langrennspigging, gå med krykker, gå på ski, eller andre liknende aktiviteter?**

☐ Aldri (gå til spm. 6) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på anstrengende fysisk aktivitet?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**6. Hvor ofte i løpet av de siste 7 dager har du drevet med øvelser eller trening for å øke muskelstyrke eller utholdenhet (for eksempel løfte vekter, gjort push-ups, sit-ups, knebøy)?**

☐ Aldri (gå til spm. 7) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på disse øvelsene for å øke muskelstyrke eller utholdenhet?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

## Aktiviteter i hjemmet

7. **Hvor ofte i løpet av de siste 7 dager har du drevet med lett husarbeid (for eksempel tørke støv, feie gulv eller vaske opp)?**

☐ Aldri (gå til spm. 8) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på lett husarbeid?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**8. Hvor ofte i løpet av de siste 7 dager har du drevet med tungt husarbeid eller gjøremål (for eksempel støvsuging, vaske gulv, vaske vinduer, vaske vegger etc.)?**

☐ Aldri (gå til spm. 9) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på tungt husarbeid eller liknende gjøremål?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**9. Hvor ofte i løpet av de siste 7 dager har du drevet med vedlikeholdsarbeid hjemme som for eksempel å snekre, male, pusse opp møbler?**

☐ Aldri (gå til spm. 10) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

På en vanlig dag hvor du drev med vedlikeholdsarbeid hjemme, hvor lang tid brukte du da på dette?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**10. Hvor ofte i løpet av de siste 7 dager har du drevet med arbeid på gårdsplass/plen (for eksempel rake løv, måke snø, kutte/trimme trær, hogge ved)**

☐ Aldri (gå til spm. 11) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på arbeid på gårdsplass/plen?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

11. **Hvor ofte i løpet av de siste 7 dager har du drevet med hagearbeid (luke, plante, etc.)**

☐ Aldri (gå til spm. 12) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på hagearbeid?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

**12. Hvor ofte i løpet av de siste 7 dager har du hatt omsorg for/pleieoppgaver for en person (for eksempel et barn, pleietrengende slektning eller en ektefelle/samboer som trenger pleie).**

☐ Aldri (gå til spm. 13) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på omsorg- eller pleie oppgaver for en annen person?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 2 t ☐ 2 - 4 timer ☐ Mer enn 4 timer

---

## Arbeidsrelatert aktivitet

**13. Hvor ofte i løpet av de siste 7 dager har hatt lønnet arbeid eller arbeidet som frivillig? (Utelat arbeid som består hovedsakelig av stillesittende arbeid som kontorarbeid, arbeid med PC, telefon/resepsjon, kjøre buss eller varebil etc.)**

☐ Aldri (gå til avslutning) ☐ Sjelden (1-2 dg) ☐ Noen ganger (3-4 dg) ☐ Ofte (5-7 dg)

I gjennomsnitt, hvor mange timer pr. dag brukte du på lønnet arbeid eller arbeid som frivillig?

☐ Mindre enn 1 t. ☐ 1 men mindre enn 4 t ☐ 5 men mindre enn 8 t ☐ 8 timer eller mer

## TRETTHET

Ved hjelp av skalaen nedenfor ber vi deg angi om du har hatt problemer med tretthet siste uke. En strek helt til venstre betyr at tretthet ikke har vært noe problem (0), en strek helt til høyre betyr at tretthet har vært et svært stort problem (100).


## SMERTE

Ved hjelp av skalaen nedenfor ber vi deg angi hvor store smerteplager du har hatt siste uke. En strek helt til venstre på linjen betyr ingen smerte (0), en strek helt til høyre betyr uutholdelig smerte (100).


Hjertelig takk!

**MÅL**

Kan du skrive ned de to viktigste målsetningene for ditt opphold ved Beitostølen Helsesportsenter (BHSS)

1. _____

2. _____

| | Ikke sikker i det hele tatt | Svært sikker |
|---|---|---|
| Hvor sikker er du på at du når disse målsetningene? | ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ | |

Hjertelig takk for at du tok deg tid til å svare!

## OM OPPHOLDET

**Dette skjemaet inneholder utsagn som er relatert til din erfaring med personellet ved Beitostølen Helsesportsenter (BHSS) under oppholdet . Vi vil gjerne vite hvordan ditt inntrykk av personellet er. Ditt svar er konfidensielt kan ikke relateres til deg. Vær så snill å være ærlig og oppriktig i din vurdering.**

| | Sterkt uenig | | | | | | Sterkt enig |
|---|---|---|---|---|---|---|---|
| Jeg føler at personalet ved BHSS gir meg muligheter og valg | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Jeg føler at personalet ved BHSS forstår meg | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Personalet ved BHSS gjør meg trygg på at jeg klarer å gjøre det bra på trening | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Personalet ved BHSS oppmuntrer meg til å stille spørsmål | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Personalet ved BHSS hører på hvordan jeg vil gjøre ting | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Personalet ved BHSS prøver å forstå hvordan jeg ser ting, før han eller hun foreslår en ny måte å gjøre ting på | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Jeg har stor tillit til personalet ved BHSS | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Jeg føler at personalet ved BHSS bryr seg om meg | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**I hvilken grad ble dine målsetninger for oppholdet ved BHSS innfridd?**

| | I svært liten grad | | | | | | | | | I svært stor grad |
|---|---|---|---|---|---|---|---|---|---|---|
| Målsetting 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Målsetting 2 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Kan du skrive ned de to viktigste målsetningene for oppfølging etter oppholdet ved BHSS?**

1. _____

2. _____

| | Ikke sikker i det hele tatt | | | | | | | | | Svært sik sikker |
|---|---|---|---|---|---|---|---|---|---|---|
| Hvor sikker er du på at du kan nå disse målsetningene | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

# Effekt av opphold ved BHSS - del C[1] LEGE

Id. nr: ☐☐☐☐

## BAKGRUNN

1.Fødselsår 19 ☐☐

2. Kjønn ☐ Kvinne ☐ Mann

3. Utdanning. Jeg har gjennomført:

☐ Grunnskole
☐ Videregående skole
☐ Universitet/høgskole: Antall år ved Universitet/høgskole: _____

4. Jeg (du kan sette flere kryss)

☐ studerer/er under utdanning
☐ er hjemmeværende
☐ er uføretrygdet
☐ er sykemeldt
☐ annet (hva……)

☐ er i lønnet arbeid
☐ er arbeidssøkende
☐ er under attføring
☐ ulønnet frivillig arbeid/aktivitetstilbud

5. Bosted

☐ Storby (mer enn 100.000)
☐ By (30 000 – 100 000)
☐ Tettsted (1000 – 30 000)
☐ Spredtbygd strøk (mindre enn 1000 innbyggere)

6. Jeg bor

☐ Alene
☐ Sammen med foreldre/foresatte
☐ Sammen med ektefelle/samboer
☐ Sammen med barn Hvor mange?.....
☐ Sammen med annen person

7. Har du servicetilbud? Besvares bare av deg som har servicetilbud:

Jeg har

☐ Personlig assistent
☐ Hjemmesykepleie
☐ Ledsagertjeneste
☐ Avlastning
☐ Hjemmehjelp
☐ Personal i bokollektiv
☐ Støttekontakt

Jeg har

☐ under 2 timer pr uke
☐ mellom 2 og 20 t pr uke
☐ mellom 20 og 60 t pr uke
☐ mer enn 60 t pr uke

## OM FUNKSJONSHEMMING

Er din funksjonshemming

- ☐ Medfødt
- ☐ Erhvervet
- ☐ Vet ikke

Hvordan arter funksjonshemmingen seg først og fremst?

- ☐ Er bevegelseshemmet, kryss av for:
  - ☐ Kan bevege meg uten hjelpemidler ute og inne
  - ☐ Kan gå men bruker krykker, stokker eller rullator
  - ☐ Kan gå, men bruker alltid rullestol over lengre avstander
  - ☐ Er helt avhengig av manuell rullestol
  - ☐ Er helt avhengig av elektrisk rullestol
- ☐ Er synshemmet, kryss av for:
  - ☐ Kan bevege meg utendørs uten ledsaging (eller førerhund)
  - ☐ Kan bevege meg utendørs uten ledsaging, men trenger ledsaging (eller førerhund) der jeg ikke er kjent
  - ☐ Trenger ledsaging (eller førerhund) når jeg skal utendørs
- ☐ Annet: Skriv……

# Approval letter from the Regional Committee for Medical Research Ethics

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Avdelingsoverlege Håkon Dalen
Beitostølen Helsesportsenter
Senervegen
2953 Beitostølen

**Regional komité for medisinsk og helsefaglig forskningsetikk Sør-Øst C (REK Sør-Øst C)**
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 46 67
Telefaks: 22 85 05 90
E-post: t.c.svanes@medisin.uio.no
Nettadresse: www.etikkom.no

**Dato: 17.12.08**
**Deres ref.:**
**Vår ref.: S-08837c 2008/21144** (oppgis ved henvendelse)

**Effekt av opphold på Beitostølen Helsesportsenter**

Komiteen behandlet søknaden 08.12.2008. Prosjektet er vurdert etter lov om behandling av etikk og redelighet i forskning av 30. juni 2006, jfr. Kunnskapsdepartementets forskrift av 8. juni 2007 og retningslinjer av 27. juni 2007 for de regionale komiteer for medisinsk og helsefaglig forskningsetikk.

*Beitostølen Helsesportsenter (BHSS) tar årlig i mot 700 personer til rehabilitering. De fleste som får tilbudet har varige, fysiske funksjonsnedsettelser. BHSS ønsker å gjennomføre en prospektiv randomisert studie der effekten av tilbudet under oppholdet, 3 måneder etter oppholdet og etter 12 måneder etter oppholdet kartlegges. Studien gjennomføres i samarbeid med Avdeling for fysikalsk medisin og rehabilitering, Ullevål Universitetssykehus. Målet er å studere effekten av oppholdet med hensyn til fysisk og mental funksjon, smerte og grad av mestring.*

Komiteen finner prosjektets tosidige siktemål, dels å studere effekten av opphold ved Beitostølen Helsesportsenter, og dels å bidra til å oppfylle intensjonene om utvikling av forskningskompetanse ved samme sted, som positive.

Dette anses likevel som ambisiøse målsetninger sett i lys av studiens design. Det er beskrevet i søknadens del **9. Vitenskapelig vurdering:** *Studien er randomisert, men av etiske grunner gis begge grupper et tilbud ved BHSS men tidsforskjøvet, slik at effekt kan evalueres.*

Komiteen er usikker på hvilke svar det reelt sett vil gi at gruppene skilles med kun en måned. At begge grupper randomiseres til samme tilbud vurderes som en svakhet i forhold til studiens funn.

Komiteen forutsetter at prosjektgruppen oppdaterer seg på feltet i forbindelse med studien, da litteraturlisten til dels synes å bestå av eldre litteratur.

I informasjonsskrivet må man spesifikt be om tilgang til pasientjournal.

**Vedtak:**
Komiteen godkjenner prosjektet under forutsetning av at ovennevnte merknad innarbeides før prosjektet igangsettes.

Komiteens avgjørelse var enstemmig.

Komiteenes vedtak etter forskningsetikklovens § 4 kan påklages (jfr. forvaltningsloven § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag. Klagen skal sendes REK Sør-Øst C (jfr. forvaltningsloven § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. forvaltningsloven § 29).

Med vennlig hilsen

Arvid Heiberg (sign.)
professor dr. med.
leder

Tor Even Svanes
komitésekretær

# Approval letter from the Norwegian Social Science Data Services

**Norsk samfunnsvitenskapelig datatjeneste AS**
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr: 985 321 884

Håkon E. Dalen
Beitostølen Helsesportsenter
Sentervegen
2953 BEITOSTØLEN

Vår dato: 10.05.2009 Vår ref: 20722 / 2 / SOJ Deres dato: Deres ref:

## TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 12.12.2008. All nødvendig informasjon om prosjektet forelå i sin helhet 13.05.2009. Meldingen gjelder prosjektet:

| | |
|---|---|
| *20722* | *Effekt av opphold på Beitostølen Helsesportsenter* |
| *Behandlingsansvarlig* | *Beitostølen Helsesportsenter, ved institusjonens øverste leder* |
| *Daglig ansvarlig* | *Håkon E. Dalen* |

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/ helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 31.12.2013, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

for
Vigdis Namtvedt Kvalheim

Synnøve Økland Jahnsen

Kontaktperson: Synnøve Økland Jahnsen tlf: 55 58 83 34
Vedlegg: Prosjektvurdering

Avdelingskontorer / District Offices:
OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrre.svarva@svt.ntnu.no
TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@sv.uit.no

# Personvernombudet for forskning

## Prosjektvurdering - Kommentar

20722

Personvernombudet finner at behandlingen kan hjemles i personopplysningsloven §§ 8 første alternativ og 9 a) (samtykke).

Personvernombudet forutsetter at det gis informasjon om følgende:
- prosjektets formål og hvilke opplysninger som registreres
- behandlingsansvarlig institusjon(er), samt navn/kontaktopplysninger til prosjektleder og sentrale prosjektmedarbeidere
- at datamaterialet vil bli behandlet konfidensielt og at forskere er underlagt taushetsplikt
- hva datamaterialet skal brukes til og hvordan det blir innsamlet, registrert og oppbevart
- anonymiseringsdato/prosjektets varighet (31.12.2013)
- understrekning av at deltakelse er frivillig, at deltagere har rett til innsyn i de opplysninger som er registrert på dem, samt at et samtykke kan trekkes tilbake så lenge studien pågår uten at man må oppgi grunn

Ved prosjektslutt 31.12.2013 anonymiseres data og kobling mellom navneliste og datamaterialet slettes. Med anonyme opplysninger forstås opplysninger som ikke på noe vis kan identifisere enkeltpersoner i et datamateriale, verken direkte gjennom navn eller personnummer, indirekte gjennom bakgrunnsvariabler eller gjennom koblingsnøkkel eller krypteringsformel.

Det bes om at informasjonsskrivet som skal benyttes i prosjektet sendes ombudet i god tid før datainnsamlingen starter.

Personvernombudet forutsetter at prosjektet er tilrådd av REK og ber om at kopi ettersendes ombudet.

# PAPERS I-III

Paper I

***Does adapted physical activity-based rehabilitation improve mental and physical functioning? A randomized trial***

Cecilie Røe, Line Preede, Håkon Dalen, Erik Bautz-Holter, Astrid Nyquist, Leiv Sandvik, Martin Saebu

*European Journal of Physical and Rehabilitation Medicine 2018 June;54:419-27 (1).*

Paper II

***One-year trajectories of mental and physical functioning during and after rehabilitation among individuals with disabilities***

Line Preede, Martin Saebu, Paul B. Perrin, Astrid Nyquist, Håkon Dalen, Erik Bautz-Holter, Cecilie Røe

*Health and Quality of Life Outcomes 2015 Aug 28;13:135 (2)*

Paper III

***Individual rehabilitation goals; what is the content of the goals and do health professionals capture this content?***

Line Preede, Helene L Soberg, Håkon Dalen, Astrid Nyquist, Reidun Jahnsen, Martin Saebu, Erik Bautz-Holter, Cecilie Røe

*Patient Preference and Adherence (submitted)*

# I

# II

Preede et al. Health and Quality of Life Outcomes (2015) 13:135
DOI 10.1186/s12955-015-0328-z

HEALTH AND QUALITY OF LIFE OUTCOMES

RESEARCH Open Access

# One-year trajectories of mental and physical functioning during and after rehabilitation among individuals with disabilities

Line Preede[1*], Martin Saebu[2], Paul. B. Perrin[3], Astrid Nyquist[2], Haakon Dalen[2], Erik Bautz-Holter[1,2] and Cecilie Røe[1,4]

## Abstract

**Purpose:** First, to evaluate the trajectories of physical and mental functioning in individuals with chronic disabilities receiving adapted physical activity-based rehabilitation. Second, to determine whether demographic factors, disability group, pain, fatigue and self-efficacy at baseline influenced these trajectories.

**Research design:** A prospective intervention study.

**Methods:** The study included 214 subjects with chronic disabilities who were admitted to a four-week adapted physical activity-based rehabilitation stay at Beitostølen Healthsports Centre. The subjects completed written questionnaires eight and four weeks before the rehabilitation, at admission to and discharge from the rehabilitation centre and again four weeks and 12 months after discharge. Multilevel models were performed to examine the trajectories of SF-12 physical and mental functioning with possible predictors.

**Results:** Time yielded a statistically significant effect on physical and mental functioning ($p < 0.001$). Low age ($p = 0.002$), no more than 2 h of personal assistance per week ($p = 0.023$), non-nervous system disability ($p = 0.019$), low pain level ($p < 0.001$) and high chronic disease-efficacy ($p = 0.007$) were associated with higher physical functioning. There was a greater improvement in physical functioning for subjects with lower chronic disease-efficacy at baseline ($p = 0.036$) and with a disability not associated with the nervous system (p = 0.040). Low fatigue ($p = 0.001$) and high chronic disease-efficacy ($p = 0.004$) predicted higher mental functioning. There was also a greater improvement in mental functioning for subjects with high fatigue ($p = 0.003$) and low chronic disease efficacy at baseline (p = 0.032).

**Conclusion:** Individuals with chronic disabilities who participated in an adapted physical activity-based intervention showed statistically significant increases in both physical and mental functioning across the 12 months after the intervention. The greatest improvement was among subjects with a high level of fatigue and low chronic disease-efficacy, as well as disabilities not associated with the nervous system, which has implications for the target groups in future rehabilitation.

## Introduction

Chronic disability is generally defined as the consequence of impairment and a difficulty in functioning at the body, personal, or societal levels in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors [1]. It may be caused by congenital or acquired diseases or by trauma and other environmental factors [2]. The burden of chronic disability is well recognized [3], and the specific problems vary according to the nature of the impairment. The World Health Organisation (WHO) has defined chronic disability to include moderate to severe health loss. It impacts a person's well-being and arises from the interaction between health conditions and contextual factors, both personal and environmental [4].

Pain is a subjective experience and the major symptom in musculoskeletal disorders [5, 6]. Pain is closely associated with disability and accounts for the largest reduction in quality of life and functioning [5]. Pain is also a major factor in neurological conditions [7], but fatigue may contribute equally to disability in some conditions [8].

Dobkin et al. (2008) defines fatigue as "a subjective lack of physical and mental energy that interferes with usual

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activity" [9]. It may be caused by the fact that activities of daily life require most of the individual's available capacity [10], which might be quite low because chronic disability is associated with a reduced physical activity level [11]. Reduced capacity and exercise form a vicious circle that, together with mobility problems, may result in restricted activities and reduced participation in both work and leisure activities. Eventually, mental and physical functioning is affected [12].

The need for rehabilitation is stressed [13]. However, the effects of rehabilitation on people with disabilities in general, and particularly over the long term, are seldom evaluated. As a result, we have little knowledge about changes and maintenance in functioning over time and possible effective measures of rehabilitation.

The term "adapted physical activity" refers to physical activities adapted to the specific needs of each individual with a disability [14]. Adapted physical activity-based rehabilitations are based on the adaptation of different activities to fit each individual's needs in the rehabilitation setting. These interventions are in general seldom evaluated, but there are some studies showing the effects of physical activity and environmental factors on physical and mental health and functioning [15–17].

In a previous study conducted at Beitostølen Health-sports Centre (BHC), both physical and mental functioning improved during a four-week adapted physical activity-based rehabilitation [18]. The study lacked long-term follow up and only assessed the outcome at one time point.

Most of the previous studies on chronic disability and rehabilitation outcomes have only one time point for follow up, usually no more than 3 months after discharge from rehabilitation. This study uses longitudinal trajectories to examine paths of variables and how they change over a specific time period. By looking at the trajectories through multilevel modelling (MLM), predictors of individual path changes can be identified. To the authors' knowledge, none of the previous studies used MLM as recommended for the analysis of longitudinal data [19].

Thus, the main aim of the present work was to evaluate the trajectories of physical and mental functioning over one year in subjects with chronic disabilities who received adapted physical activity-based rehabilitation. Second, we wanted to determine whether demographic factors, type of disability, pain, fatigue and self-efficacy at baseline influenced the trajectories of physical and mental functioning.

## Materials and methods

### Design

The study design was a prospective intervention study.

### Participants and procedures

Subjects with chronic disabilities as defined by WHO, aged 18 years to 73 years (men and woman) and admitted to a four-week rehabilitation stay at BHC were assessed for eligibility. Subjects consenting to participating in and completing the rehabilitation programme were included. Written invitations with information about the study were sent to the participants. Those who accepted the invitation provided written informed consent. The study was approved by the Regional Medical Committee for Research Ethics in Norway (S-08837c 2008/21144). All subjects were examined by a medical doctor upon admission to the rehabilitation centre and by health professionals according to the subject's specific needs. Physiotherapists, nurses, social workers, and sports rehabilitation specialists comprised the other professions involved. A team was organized for each subject. On the second day, the team and the subject developed a detailed, goal-oriented plan for the rehabilitation.

Between September 2010 and December 2012, data were collected by a written questionnaire administered to the participants eight (baseline) and four weeks before rehabilitation, at admission to and discharge from rehabilitation and again at four weeks and twelve months after discharge (follow-up).

### Rehabilitation programme at BHC

The rehabilitation programme at BHC is based on the vision of adapted physical activity and adapts physical activities to the needs of the individuals [14].

Goal planning is an essential part of the rehabilitation process to enhance subject autonomy, treatment adherence, and feelings of self-efficacy. It provides a basis for individualized treatments through a structured goal-planning process. The subject is an active participant in the rehabilitation process, and the activity of the rehabilitation team is goal oriented and takes into account the preferences of the subject.

The rehabilitation includes social and cultural activities and extensive use of outdoor natural facilities year round. A

**Table 1** Characteristics of the included subjects

| Variables | | *n* = 214 | % |
|---|---|---|---|
| Age (mean) | | 51.4 | |
| Gender | Female | 119 | 56 |
| | Male | 95 | 44 |
| Living in town/township (>30 000) | | 120 | 56 |
| Education (university level) | | 95 | 44 |
| Employed | | 76 | 36 |
| Personal assistance (>2 h/week) | | 42 | 20 |
| Living alone | | 74 | 35 |
| Target group | Nervous system | 102 | 48 |
| | Musculoskeletal | 64 | 30 |
| | Others | 48 | 22 |

**Table 2** A hierarchical linear model with time, demographic factors, self-efficacy, fatigue and pain as predictors of Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary

| Predictor variable | b-weight | SE | df | *t* | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|---|---|
| | | | | | | Lower | Upper |
| Time | 0.73 | 0.10 | 986.93 | 7.61 | ***0.000 | 0.54 | 0.91 |
| Sex | 0.16 | 0.92 | 213.76 | 0.17 | 0.862 | −1.65 | 1.97 |
| Age | −0.11 | 0.04 | 215.35 | −3.16 | **0.002 | −0.18 | −0.04 |
| Employment | 2.23 | 0.98 | 213.24 | 2.29 | *0.023 | 0.31 | 4.16 |
| Living alone | 0.03 | 0.95 | 214.09 | −0.26 | 0.979 | −1.85 | 1.90 |
| Living in town (>30') | 0.66 | 0.95 | 213.31 | 0.69 | 0.489 | −1.21 | 2.52 |
| Education | 0.10 | 0.96 | 212.89 | 0.10 | 0.917 | −1.79 | 1.99 |
| Personal assistance (>2 h/week) | −2.26 | 1.16 | 215.12 | −1.95 | 0.052 | −4.54 | 0.02 |
| Disability | 2.17 | 0.92 | 214.16 | 2.35 | *0.019 | 0.35 | 3.98 |
| Exercise-efficacy | 0.40 | 0.25 | 214.22 | 1.63 | 0.105 | −0.01 | 0.89 |
| Social-efficacy | 0.30 | 0.22 | 213.31 | 1.34 | 0.180 | −0.14 | 0.74 |
| Chronic disease-efficacy | 0.90 | 0.33 | 215.64 | 2.74 | **0.007 | 0.25 | 1.56 |
| Fatigue | 0.00 | 0.02 | 213.22 | −0.01 | 0.990 | −0.03 | 0.03 |
| Pain | −0.09 | 0.02 | 214.15 | −4.35 | ***0.000 | −0.13 | −0.05 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

wide range of services is offered, including adaptation of the environment, technical aids, and individual instruction. The programme is intensive, with 2 to 5 h of physical activity a day, six days a week.

Most of the activities are arranged in groups. The group setting is considered important, encouraging participants to work together, give feedback to each other and exchange activity experiences. During their stay, the participants' schedules are regularly assessed and adjusted when necessary. The range of activities that the rehabilitation centre offers includes swimming, cross-country skiing, alpine skiing, horseback-riding, aerobics, kayaking and other activities, which allows each individual to determine the activities best suited to him or her.

### Assessments

Demographic data, including age, gender, education, residence, employment, and need for personal assistance, were recorded during an interview with the medical

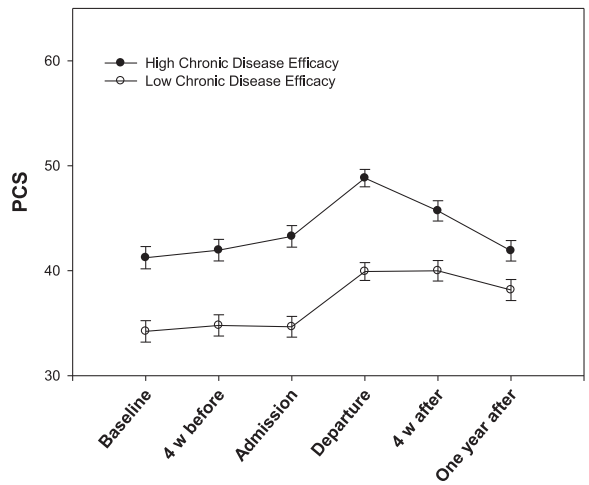


**Fig. 1** Change in Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary (PCS) for the high and low chronic disease-efficacy groups with standard error

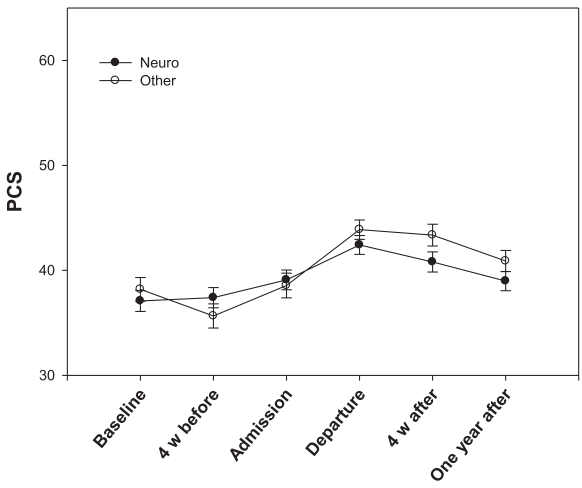


**Fig. 2** Change in Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary (PCS) for the disability groups with standard error

**Table 3** A hierarchical linear model with statistically significant predictors from Table 2 and their interactions with time as predictors of Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary

| Predictor variable | b-weight | SE | df | *t* | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|---|---|
| | | | | | | Lower | Upper |
| Time | 0.67 | 0.15 | 987.89 | 4.40 | ***0.000 | 0.37 | 0.97 |
| Age | −0.11 | 0.04 | 339.34 | −2.90 | **0.004 | −0.19 | −0.04 |
| Employment | 3.67 | 1.07 | 335.55 | 3.43 | **0.001 | 1.57 | 5.78 |
| Disability | 1.05 | 1.03 | 338.45 | 1.01 | 0.313 | −0.99 | 3.08 |
| Chronic disease-efficacy | 1.60 | 0.30 | 339.74 | 5.36 | ***0.000 | 1.01 | 2.18 |
| Pain | −0.10 | 0.02 | 339.80 | −4.89 | ***0.000 | −0.14 | −0.06 |
| Time *Age | 0.00 | 0.01 | 989.90 | .12 | 0.906 | −0.01 | 0.02 |
| Time *Employment | −0.38 | 0.20 | 985.69 | −1.91 | 0.056 | −0.77 | 0.01 |
| Time *Disability | 0.40 | 0.19 | 987.44 | 2.06 | *0.040 | 0.02 | 0.78 |
| Time *Chronic disease-efficacy | −0.12 | 0.06 | 989.67 | −2.10 | *0.036 | −0.23 | −0.01 |
| Time *Pain | 0.01 | 0.00 | 990.81 | 1.61 | 0.107 | −0.00 | 0.01 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

doctor on admission to the rehabilitation centre. Diagnoses were obtained from the referral letter for the rehabilitation stay and were validated by the doctor at admission. The main reasons for disability were grouped according to disorders of the nervous system, disorders of the musculoskeletal system and other disorders.

Perceived physical and mental functioning were measured by the Medical Outcomes Study 12-item Short Form Health Survey (SF-12, licence number QM 027126) [20, 21]. The SF-12 consists of 12 items and yields a Physical Component Summary and Mental Component Summary, which are intended to reflect perceived physical and mental functioning, respectively. The SF-12 has been shown to capture approximately 90 % of the variance in the SF-36 and to reflect the same 8 dimensions [20, 21]. The SF-12 is far less time consuming than the SF-36. It was regarded by the subjects as easier to complete and was chosen to increase the response rate after discharge. The answers were given on a Likert-type scale with 3 or 5 scoring levels for the different items. The Physical and Mental Component Summary (PCS and MCS) norm-based scores for the SF-12 were calculated using the reversed scores of questions 1, 8, 9 and 10 [22]. Mean PCS and MCS for a Norwegian reference population were used for comparison of the study population's mean scores. The reference scores are 50.3 (SD 8.8) for PCS and 50.6 (SD 9.9) for MCS [20].

The Norwegian versions of three separate scales were used to capture the different elements of self-efficacy. Efficacy for managing chronic disease (Chronic disease-efficacy) was measured by the Self-Efficacy for Managing Chronic Disease 6-Item Scale [23]. A sample item is as follows: "How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?" Responses were given on a 10-point Likert-type scale ranging from *not at all confident* (1) to *totally confident* (10). The scale has been shown to be valid in a sample with 489 subjects with chronic disease and has demonstrated high internal consistency (0.91).

Efficacy for exercise regularly (Exercise-efficacy) was measured by the Exercise Regularly Scale (3-item scale) in the Stanford Chronic Disease Self-Efficacy Scales [24]. A sample item is, "How confident are you that you can do aerobic exercise such as walking, swimming, or bicycling three to four times each week?" Responses were given on a 10-point Likert-type scale ranging from *not at all confident* (1) to *totally confident* (10). The scale has shown good validity in a sample with 478 subjects

**Table 4** Change in Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary for subjects with low chronic disease-efficacy

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 102$) | 5.31 | 7.60 | 0.000*** | 3.82 | 6.81 |
| Departure – 12 months ($n = 86$) | −2.37 | 6.85 | 0.002** | −3.84 | −0.91 |
| Baseline – 12 months ($n = 91$) | 3.16 | 7.40 | 0.000*** | 1.62 | 4.70 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

**Table 5** Change in Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary for subjects with high chronic disease-efficacy

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 102$) | 5.31 | 8.53 | 0.000*** | 3.63 | 6.98 |
| Departure – 12 months ($n = 91$) | −4.90 | 7.91 | 0.000*** | −6.54 | −3.25 |
| Baseline – 12 months ($n = 94$) | 0.63 | 8.66 | 0.484 | −1.15 | 2.40 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

with chronic disease (the internal consistency was 0.83, and the test-retest reliability was 0.86).

Efficacy for social/recreational activities (Social-efficacy) was measured by the Social/Recreational Activities scale (2-item scale) in the Stanford Chronic Disease Self-Efficacy Scales [24]. A sample item is, "How confident are you that you can continue to do your hobbies and recreation?" Responses were given on a 10-point Likert-type scale ranging from *not at all confident* (1) to *totally confident* (10). The scale has shown to be valid in a sample with 478 subjects with chronic disease (the internal consistency was 0.84, and the test-retest reliability was 0.84).

Pain and fatigue were measured by visual analogue scales (VAS) 100 mm long on a scale of 0–100 ("no pain" to "intolerable pain" and, for fatigue, "not a problem" to "a very big problem") [25, 26].

### Statistical methods

*T*-test and chi-square statistics were applied to compare the subjects dropping out with those completing the study. Multi-level models (MLMs) were performed to examine whether linear trajectories of the SF-12 physical and mental scores over one year could be predicted by time, sex, age, type of disability, education, employment, personal assistance, pain, fatigue, and self-efficacy. These variables were all entered simultaneously as fixed effects into the models. For the purpose of the analysis, the disability categories were merged into two groups (those with nervous system disabilities and those with other disabilities). The respective mean was subtracted from all variables for the purpose of centring them before being entered into the MLM. SF-12 scores at each of the six time points (baseline, four weeks before admission, at admission to and discharge from rehabilitation, four weeks after discharge, and 12 months after discharge) were entered as the dependent variables in each model. A second set of two MLMs was then run to examine whether any of the statistically significant fixed effects in the first two models interacted significantly with time in the prediction of participants' physical and mental functioning trajectories, which would indicate that these trajectories changed differentially over time as a function of one of the predictors.

Predictors with significant interactions with time were dichotomized around their mean level (high/low), and paired sample *t*-tests were also conducted to evaluate changes from baseline to the 12-month follow up for subjects with high and low levels of the predictor. All data were analysed using SPSS, version 21. A significance level of 0.05 was adopted.

## Results

### Participants

From the subjects admitted to rehabilitation, 321 were assessed for eligibility and 304 were eligible after exclusion. The exclusion criteria were insufficient knowledge of Norwegian to fill out the questionnaires and severe cognitive disorders. Of the eligible subjects, 246 subjects consented to participation and 32 dropped out before or during the intervention, which resulted in 214 subjects who completed rehabilitation and were included in the study. The gender (*56 %* females) and age (*47 years*) of the 32 subjects who dropped out did not differ significantly from the subjects included in the data analysis (Chi square = 0.000,$p = 0.985$ *and* $F = 2.948$, $p = 0.087$, respectively). There were no significant differences in the distribution of disability groups between the 32 subjects who dropped out (*50 % nervous system, 31 % musculoskeletal*

**Table 6** Change in Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary for subjects with disability not associated with the nervous system

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 109$) | 5.12 | 8.57 | 0.000*** | 3.50 | 6.75 |
| Departure – 12 months ($n = 91$) | −3.22 | 7.93 | 0.000*** | −4.87 | −1.57 |
| Baseline – 12 months ($n = 94$) | 2.47 | 8.50 | 0.006** | 0.73 | 4.21 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

**Table 7** Change in Medical Outcomes Study 12-item Short Form Health Survey Physical Functioning Component Summary for subjects with disability associated with the nervous system

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 95$) | 5.53 | 7.47 | 0.000*** | 4.01 | 7.05 |
| Departure – 12 months ($n = 86$) | −4.15 | 7.02 | 0.000*** | −5.66 | −2.65 |
| Baseline – 12 months ($n = 91$) | 1.26 | 7.76 | 0.126 | −0.36 | 2.87 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

*and 19 % others*) and the 214 subjects who completed the programme (see Table 1) (chi square =0.384, $p = 0.944$). Reported musculoskeletal problems included rheumatic diseases as the most frequent diagnostic entities. Neurological problems included cerebral palsy, multiple sclerosis and inherited motor neuron disorders as the most frequent diagnostic entities. Cerebrovascular diseases, spinal cord injuries and visual impairments were the other reported reasons for disability. The median duration of disease that caused disability was 18.1 years.

Of the included subjects, 61 did not complete one or more of the 6 questionnaires. They were still included in the MLM, which is robust to missing data. Table 1 shows the characteristics of the included subjects ($n = 209$).

### Trajectory of physical functioning

The physical functioning at baseline was rather low, with a mean PCS score of 37.38 (SD 9.60). The MLM showed that physical functioning improved across the six time points ($p < 0.001$) (Table 2), with the main improvement being between admission to and discharge from rehabilitation (Figs. 1 and 2). The mean PCS at discharge was 42.48 (SD 8.16), and at the 12-month follow up, the mean was 39.33 (SD 9.16).

A younger age, employment and disability not associated with the nervous system predicted better physical functioning over time ($p = 0.002$, $p = 0.023$ and $p = 0.019$, respectively). Furthermore, subjects with higher chronic disease-efficacy ($p = 0.007$) as well as lower levels of pain ($p < 0.001$) also had better physical functioning (Table 2).

There was a statistically significant interaction between disability and time ($p = 0.040$) and between chronic disease-efficacy and time ($p = 0.036$). The improvement in physical functioning during and after rehabilitation was greater in subjects with a disability not associated with the nervous system and with lower chronic disease-efficacy at baseline (Table 3). After dichotomizing into low and high chronic disease-efficacy around the mean of 6.55, the two groups had the same improvement in physical functioning from baseline to discharge, but the subjects with higher self-efficacy had a greater decline from discharge to the 12-month follow up (Fig. 1). At

**Table 8** A hierarchical linear model with time, demographic factors, self-efficacy, fatigue and pain as predictors of Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary

| Predictor Variable | b-weight | SE | df | *t* | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|---|---|
| | | | | | | Lower | Upper |
| Time | 0.85 | 0.11 | 986.06 | 7.39 | ***0.000 | 0.62 | 1.07 |
| Sex | −1.50 | 1.00 | 211.55 | −1.50 | 0.135 | −3.46 | 0.47 |
| Age | 0.02 | 0.04 | 213.42 | 0.43 | 0.671 | −0.06 | 0.09 |
| Employment | −0.39 | 1.06 | 210.95 | −0.37 | 0.714 | −2.49 | 1.71 |
| Living alone | −1.17 | 1.03 | 211.95 | −1.14 | 0.257 | −3.21 | 0.86 |
| Living in town (>30') | 0.79 | 1.03 | 211.04 | 0.77 | 0.443 | −1.24 | 2.82 |
| Education | 0.45 | 1.04 | 210.54 | 0.43 | 0.667 | −1.61 | 2.51 |
| Personal assistance (>2 h/week) | 1.91 | 1.26 | 213.15 | 1.52 | 0.131 | −0.57 | 4.40 |
| Disability | −0.73 | 1.00 | 212.04 | −0.73 | 0.465 | −2.71 | 1.24 |
| Exercise-efficacy | 0.41 | 0.27 | 212.12 | 1.52 | 0.129 | −0.12 | 0.95 |
| Social-efficacy | −0.11 | 0.24 | 211.04 | −0.44 | 0.663 | −0.59 | 0.37 |
| Chronic disease-efficacy | 1.05 | 0.36 | 213.76 | 2.93 | **0.004 | 0.34 | 1.76 |
| Fatigue | −0.06 | 0.02 | 210.94 | −3.22 | **0.001 | −0.09 | −0.02 |
| Pain | −0.04 | 0.02 | 212.04 | −1.78 | 0.077 | −0.08 | 0.00 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

the 12-month follow up, physical functioning significantly improved compared to baseline, with a mean of 3.16 (SD 7.40) in the low chronic disease-efficacy group ($p < 0.001$) (Table 4). Subjects with high chronic disease-efficacy at baseline showed no statistically significant improvement in physical functioning at the 12-month follow up (mean change 0.63, SD 8.66, $p = 0.484$) (Table 5). Paired comparisons of subjects with or without disabilities associated with the nervous system also showed a significant improvement in both groups from baseline to discharge, but subjects with disabilities not associated with the nervous system did not show as great a decrease as those with a nervous system-associated disability (Fig. 2). At the 12-month follow up, physical functioning significantly improved compared to baseline with a mean of 2.47 (SD 8.50) in the group with disabilities not associated with the nervous system ($p < 0.006$) (Table 6). Subjects with nervous system disabilities showed no statistically significant improvement in physical functioning at the 12-month follow up (mean change 1.26, SD 7.76, $p = 0.126$) (Table 7).

### Trajectory of mental functioning

Subjects' baseline values of mental functioning showed a mean MCS score of 49.52 (SD 10.28). The MLM showed that mental functioning improved across the six time points ($p < 0.001$) (Table 8), with the main improvement being between admission to and discharge from rehabilitation (Figs. 3 and 4). The mean MCS at discharge was 56.35 (SD 8.25). At the 12-month follow up, the mean was 52.40 (SD 10.00).

Subjects with higher chronic disease-efficacy ($p = 0.004$) and lower fatigue ($p = 0.001$) had better mental functioning over time (Table 8).

There was a statistically significant relationship between time and chronic disease efficacy ($p = 0.032$) and between time and fatigue ($p = 0.003$). The improvement in mental functioning during and after rehabilitation was greater in subjects with low levels of chronic disease-efficacy and high levels of fatigue (Table 9). Data were dichotomized into high and low chronic disease-efficacy and fatigue around the means of 6.55 and 49.37, respectively. The group of subjects with high levels of fatigue improved their mental functioning more from baseline to discharge compared to the low-level group, but the decline after discharge was also greater (Fig. 3). Despite the decline, subjects with high levels of fatigue had a significant improvement in mental functioning from baseline to the 12-month follow up (mean difference 3.65, SD 8.46, $p < 0.001$) (Table 10). Subjects with low levels of fatigue had no statistically significant change in mental functioning during the same time period (mean difference 1.29, SD 9.71, $p = 0.212$) (Table 11). Subjects with low chronic disease-efficacy at baseline also improved more in mental functioning from baseline to discharge from rehabilitation (Fig. 4). Although they had a slightly greater decline after discharge than the high chronic disease-efficacy group, subjects with low chronic disease-efficacy had a significant improvement in mental functioning from baseline to the 12-month follow up (mean difference 3.65, SD 9.86, $p = 0.001$) (Table 12). Subjects with high chronic disease-efficacy at baseline showed no statistically significant improvement in mental functioning at the 12-month follow up (mean difference 1.39, SD 8.30, $p = 0.108$) (Table 13).

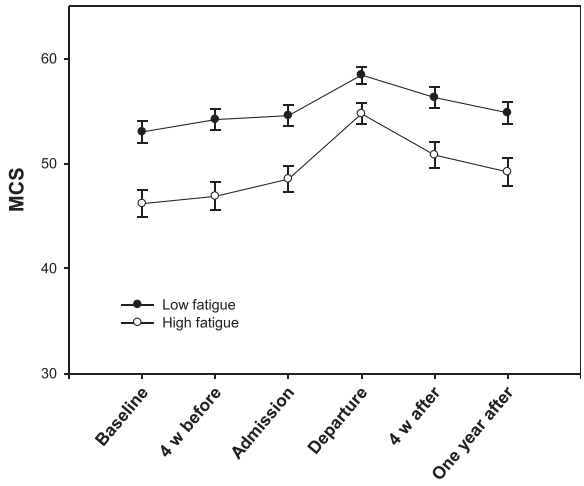


**Fig. 3** Change in Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary (MCS) for subjects with high and low levels of fatigue with standard error

## Discussion

The results show that both mental and physical functioning improved during rehabilitation and that improvement

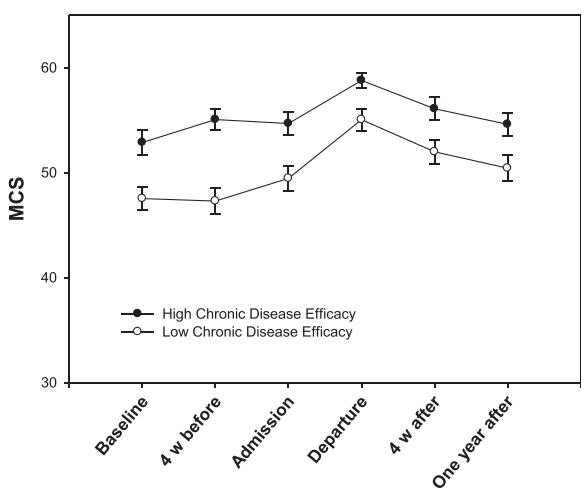


**Fig. 4** Change in Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary (MCS) for the high and low chronic disease-efficacy groups with standard error

**Table 9** A hierarchical linear model with statistically significant predictors from Table 6 and their interactions with time as predictors of Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary

| Predictor variable | b-weight | SE | df | *t* | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|---|---|
| | | | | | | Lower | Upper |
| Time | 0.88 | 0.11 | 985.97 | 7.73 | ***0.000 | 0.66 | 1.10 |
| Chronic disease-efficacy | 1.65 | 0.33 | 358.49 | 4.99 | ***0.000 | 1.00 | 2.30 |
| Fatigue | −0.10 | 0.02 | 357.72 | −5.09 | ***0.000 | −0.14 | −0.06 |
| Time * Chronic disease-efficacy | −0.14 | 0.07 | 987.18 | −2.15 | *0.032 | −0.27 | −0.01 |
| Time * Fatigue | 0.01 | 0.00 | 985.18 | 3.00 | **0.003 | 0.00 | 0.02 |

Note. * = $p < .05$; ** = $p < .01$; *** = $p < .001$

remained statistically significant at the 12-month follow up compared to baseline. This supports previous studies indicating an association between rehabilitation and improvement in mental and physical functioning up to three months after rehabilitation [18, 27] and provides new knowledge about the longer-term effects of rehabilitation.

Physical functioning for this sample was low compared to a Norwegian reference population [20]. Previous studies have also found a significant reduction in physical functioning in populations with chronic diseases [12, 28]. Although the sample had a significant improvement in physical functioning from baseline to discharge, physical functioning was still 15 % below the reference population, which is expected considering the nature of the disability in subjects referred to rehabilitation at BHC.

The mental functioning was almost in line with the Norwegian reference population [20]. This is similar to what has been shown in previous research [29, 30]. During the intervention, mental functioning rose to a higher level than the reference population. BHC may be a perfect setting to improve mental functioning for subjects with disabilities, as it is an environment away from everyday life struggles, brings together people who have similar disabilities and health problems, and is guided by well-trained instructors and health workers.

Mental and physical functioning started to improve even before admission to the rehabilitation programme. This might be because of expectations that come from the subjects looking forward to the programme or because they engaged in more exercise to start to improve their functioning before the intervention started. However, the effects of expectations are mainly studied regarding outcome of treatment [31].

In the present study, the improvement in mental and physical functioning from baseline to discharge was more than twice the reported detectable changes of 3 for MCS and 2–3 for PCS [32]. Although the SF-12 is a generic measurement, the clinical significance of changes may vary across disabilities and be influenced by environmental factors. Large variations in clinically important differences have also been reported in the literature [33–36]. Because of the detected change, the improvement in mental and physical functioning from baseline to discharge in this study is of high clinical relevance. With the decline after discharge, the improvements we found in both mental and physical functioning at the 12-month follow up are just below the levels of clinical relevance (2.88 and 1.99, respectively).

The results also show, not surprisingly, that subjects with lower age, those who are employed and those who have disabilities not associated with the nervous system had higher physical functioning over time. Previous findings support the importance of young age in rehabilitation [37–39].

Pain, fatigue and self-efficacy at baseline had effects on the trajectories of physical and mental functioning. Both higher efficacy for managing chronic disease and lower pain predict higher physical functioning at each time point. Higher efficacy for managing chronic disease and lower fatigue predict higher mental functioning at each time point. This result supports the findings of previous

**Table 10** Change in Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary for subjects with high levels of fatigue

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 114$) | 8.69 | 9.13 | 0.000*** | 7.00 | 10.39 |
| Departure – 12 months ($n = 90$) | −5.27 | 7.85 | 0.000*** | −6.91 | −3.62 |
| Baseline – 12 months ($n = 95$) | 3.65 | 8.46 | 0.000*** | 1.93 | 5.37 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

**Table 11** Change in Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary for subjects with low levels of fatigue

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 90$) | 4.35 | 9.87 | 0.000*** | 2.27 | 6.40 |
| Departure – 12 months ($n = 87$) | −3.37 | 8.35 | 0.000*** | −5.15 | −1.59 |
| Baseline – 12 months ($n = 90$) | 1.29 | 9.71 | 0.212 | −0.75 | 3.32 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

studies that investigated the association between self-efficacy and functioning [29, 40, 41] and the association between fatigue and functioning [27, 38].

Subjects with high levels of fatigue at baseline improved their mental functioning, while subjects with low levels did not have any improvement at the 12-month follow up. The biggest improvements happened during the intervention period, where both groups improved. The high-fatigue group degraded more than the low-fatigue group after discharge, but they still showed a significant improvement at the 12-month follow up. It is interesting that the intervention specifically improved the long-term mental functioning of the subjects with high fatigue because it is well known that fatigue impacts a person's functioning [42–44]. This means that even though the high-fatigue group still had a lower level mental function than the low-fatigue group, the intervention tended to improve it long term.

It is interesting that subjects with lower efficacy for managing chronic disease at baseline had greater improvement in both mental and physical functioning over time than subjects with higher efficacy. This group started their rehabilitation with many insecurities about managing their disease, which might have held them back with regard to improvement. After some time in the BHC environment, it appeared as though they became more secure and observed that others could manage the same disease. This improvement in security might last and help them to maintain their physical and mental functioning after returning to their home environment. It is also important to note that the low-efficacy group maintained their physical functioning without degrading too much after returning to their home environment. This study did not investigate reasons for the maintenance of functioning after discharge, but it is likely that the intervention is a factor. Subjects with high efficacy for managing chronic disease showed no improvement at the 12-month follow up, even though they did improve their mental and physical functioning during the intervention. The fact that subjects with low chronic disease-efficacy at baseline had a greater improvement in functioning was also stated in a previous study on individuals with neuromuscular diseases and multiple sclerosis [45], although that study measured outcome over a shorter time period. These effects could also be the result of statistical regression to the mean over time, whereby participants with a low efficacy at baseline could also be those with the lowest levels of physical and mental functioning and therefore be the groups who have the most room for improvement in functioning during rehabilitation.

### Strengths and limitations

A strength of this study is the use of multi-level modelling, which handles time with unequal spacing and is flexible in handling missing data [19]. This makes it possible to include subjects who did not complete the questionnaire at one or more of the six time points and thereby increases statistical power and improves precision.

Very few studies have evaluated the effects of an adapted physical activity-based intervention. To our knowledge Sprott et al. is one of very few studies that has focused on adapted physical activity for pain patients [46]. Additionally, a study focusing on the effects of equine-assisted activities and therapies for children with cerebral palsy exists [47]. This study contributes important knowledge about the effects of an adapted physical activity-based intervention in a generalized group of subjects with chronic disabilities.

**Table 12** Change in Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary for subjects with low chronic disease-efficacy

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 102$) | 7.79 | 10.69 | 0.000*** | 5.69 | 9.89 |
| Departure – 12 months ($n = 86$) | −4.45 | 8.31 | 0.000*** | −6.23 | −2.66 |
| Baseline – 12 months ($n = 91$) | 3.65 | 9.86 | 0.001** | 1.60 | 5.70 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

**Table 13** Change in Medical Outcomes Study 12-item Short Form Health Survey Mental Functioning Component Summary for subjects with high chronic-disease efficacy

| | Mean change | SD | *p*-value | 95 % Confidence Interval | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Baseline – Departure ($n = 102$) | 5.76 | 8.49 | 0.000*** | 4.09 | 7.42 |
| Departure – 12 months ($n = 91$) | −4.23 | 7.99 | 0.000*** | −5.90 | −2.57 |
| Baseline – 12 months ($n = 94$) | 1.39 | 8.30 | 0.108 | −0.31 | 3.09 |

Note. *= $p < .05$; **= $p < .01$; ***= $p < .001$

The data collection at admission and discharge occurred at the rehabilitation facility, while data from all other time points were collected in the subjects' home environment. This might have contributed to bias due to environmental influence. The benefit of subjects completing measures at the facility, and thereby making it a part of the rehabilitation stay, could have decreased the drop-out rate at these time points.

We cannot exclude the possibility of an improvement in physical and mental functioning over time without a rehabilitation stay. However, taking into account that problems the study population face have had a long duration and that there was no improvement during the 8 weeks prior to admission, this improvement seems unlikely. To further investigate the change of improvement, a control group is needed. Because the programme must be provided for those who are in need, it would be ethically challenging to follow a similar group for 12 months without giving them the same intervention during that period.

The subjects who attend rehabilitation at BHC might not fully reflect the Norwegian population with chronic disabilities. It is, of course, a voluntary decision to participate in a rehabilitation stay, and the subjects who chose it might be more motivated to improve their functional skills and physical capacity, as well as to meet new people in such an environment. They also have to be able to leave their everyday environment, family and work situation for a period of 4 weeks to attend rehabilitation.

We have used the word functioning to describe The Medical Outcome Studies Short-Form mental and physical component scores (MCS and PCS). Earlier research has used terms such as mental and physical health, mental and physical functioning and health-related quality of life [18, 48, 49]. The ability of this type of instrument to reflect relevant changes in chronic disabilities has been debated [50], and it has also been debated whether quality of life is a good term regarding the content of these measurements [51]. The present study supports the feasibility of the SF-12 instrument, at least when viewed as a measure of functioning.

This study shows how the trajectories of physical and mental functioning in individuals with disabilities vary over the course of rehabilitation. An adapted physical activity-based intervention is associated with improvements in both physical and mental functioning, and this improvement is statistically significant 12 months after the intervention. An important goal of the rehabilitation programme is sustained long-term improvement. The clinical implication of these results could be that rehabilitation programmes similar to the one at BHC can assess participant self-efficacy and help individuals with disabilities explore the ways in which their self-efficacy influences their engagement in rehabilitation and possibly the resulting gains.

Future research should focus on causes of the decrease in mental and physical functioning after discharge and on trajectories with a longer follow-up period to look for further changes in outcomes. Such knowledge could contribute to improvements in the long-term rehabilitation care for individuals with disabilities.

#### Competing interests
The authors declare that they have no competing interests.

#### Authors' contributions
LP planned the approach to the present paper, performed the statistical analysis and drafted the manuscript. MS participated in the design, data collection and coordination of the study and helped with the statistical analysis. PP helped with the statistical analysis and drafting of the manuscript. AN, HD and EBH participated in the design and coordination of the study. CR participated in the design of the study, helped with the statistical analyses and helped to draft the manuscript. All authors read and approved the final manuscript.

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#### References
1. Leonardi M, Bickenbach J, Ustun TB, Kostanjsek N, Chatterji S, MHADIE Consortium. The definition of disability: what is in a name? Lancet. 2006;368(9543):1219–21.
2. Bauer UE, Briss PA, Goodman RA, Bowman BA. Prevention of chronic disease in the 21st century: elimination of the leading preventable causes of premature death and disability in the USA. Lancet. 2014;384(9937):45–52.
3. Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of

Persons with Disabilities. National Institutional Frameworks and Human Rights of Persons with Disabilities. Background conference document. United Nations General Assembly. 2006 [cited 2015 May 5]; Available from: http://www.un.org/esa/socdev/enable/rights/ahc8documents.htm.
4. WHO. World report on disability. 2011 [cited 2015 May 5]; Available from: http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1.
5. Chandratre P, Roddy E, Clarson L, Richardson J, Hider SL, Mallen CD. Health-related quality of life in gout: a systematic review. Rheumatology (Oxford). 2013;52(11):2031–40.
6. Pain terms: a list with definitions and notes on usage. Recommended by the IASP Subcommittee on Taxonomy. Pain. 1979; 6(3):249.
7. Fine PG. Long-term consequences of chronic pain: mounting evidence for pain as a neurological disease and parallels with other chronic disease states. Pain Med. 2011;12(7):996–1004.
8. Rombaut L, Malfait F, Cools A, De Paepe A, Calders P. Musculoskeletal complaints, physical activity and health-related quality of life among patients with the Ehlers-Danlos syndrome hypermobility type. Disabil Rehabil. 2010;32(16):1339–45.
9. Dobkin BH. Fatigue versus activity-dependent fatigability in patients with central or peripheral motor impairments. Neurorehabil Neural Repair. 2008;22(2):105–10.
10. Kemp B, Thompson L. Aging and spinal cord injury: medical, functional, and psychosocial changes. SCI Nurs. 2002;19(2):51–60.
11. Boslaugh SE, Andresen EM. Correlates of physical activity for adults with disability. Prev Chronic Dis. 2006;3(3):A78.
12. Rijken M, van Kerkhof M, Dekker J, Schellevis FG. Comorbidity of chronic diseases: effects of disease pairs on physical and mental functioning. Qual Life Res. 2005;14(1):45–55.
13. Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. J Rehabil Res Dev. 2008;45(2):315–22.
14. Hutzler Y, Sherrill C. Defining adapted physical activity: international perspectives. Adapt Phys Activ Q. 2007;24(1):1–20.
15. Maruf FA, Akinpelu AO, Salako BL. Self-reported quality of life before and after aerobic exercise training in individuals with hypertension: a randomised-controlled trial. Appl Psychol Health Well Being. 2013;5(2):209–24.
16. Smart NA, Murison R. Rate of change in physical fitness and quality of life and depression following exercise training in patients with congestive heart failure. Congest Heart Fail. 2013;19(1):1–5.
17. Lauret GJ, van Dalen DC, Willigendael EM, Hendriks EJ, de Bie RA, Spronk S, et al. Supervised exercise therapy for intermittent claudication: current status and future perspectives. Vascular. 2012;20(1):12–9.
18. Roe C, Dalen H, Lein M, Bautz-Holter E. Comprehensive rehabilitation at Beitostolen Healthsports Centre: influence on mental and physical functioning. J Rehabil Med. 2008;40(6):410–7.
19. Kwok OM, Underhill AT, Berry JW, Luo W, Elliott TR, Yoon M. Analyzing Longitudinal Data with Multilevel Models: An Example with Individuals Living with Lower Extremity Intra-articular Fractures. Rehabil Psychol. 2008;53(3):370–86.
20. Gandek B, Ware JE, Aaronson NK, Apolone G, Bjorner JB, Brazier JE, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. J Clin Epidemiol. 1998;51(11):1171–8.
21. Ware Jr J, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care. 1996;34(3):220–33.
22. Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. How to Score Version 2 of the SF-12(R) Health Survey. Lincoln: QualityMetric Incorporated; 2002.
23. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract. 2001;4(6):256–62.
24. Stewart A, Ritter P, González V, Laurent D, Lynch J. Outcome Measures for Health Education and other Health Care Interventions. Thousand Oaks: Sage Publications; 1996.
25. Wolfe F. Fatigue assessments in rheumatoid arthritis: comparative performance of visual analog scales and longer fatigue questionnaires in 7760 patients. J Rheumatol. 2004;31(10):1896–902.
26. Huskisson EC. Measurement of pain. Lancet. 1974;2(7889):1127–31.
27. McCullagh R, Fitzgerald AP, Murphy RP, Cooke G. Long-term benefits of exercising on quality of life and fatigue in multiple sclerosis patients with mild disability: a pilot study. Clin Rehabil. 2008;22(3):206–14.
28. Hays RD, Wells KB, Sherbourne CD, Rogers W, Spritzer K. Functioning and well-being outcomes of patients with depression compared with chronic general medical illnesses. Arch Gen Psychiatry. 1995;52(1):11–9.
29. van der Slot WM, Nieuwenhuijsen C, van den Berg-Emons RJ, Wensink-Boonstra AE, Stam HJ, Roebroeck ME, et al. Participation and health-related quality of life in adults with spastic bilateral cerebral palsy and the role of self-efficacy. J Rehabil Med. 2010;42(6):528–35.
30. Redfors YD, Olaison S, Karlsson J, Hellgren J, Moller C. Hearing-related, health-related quality of life in patients who have undergone otosclerosis surgery: A long-term follow-up study. Int J Audiol. 2015. 54(2):63-9.
31. Clark AM, King-Shier KM, Spaling MA, Duncan AS, Stone JA, Jaglal SB, et al. Factors influencing participation in cardiac rehabilitation programmes after referral and initial attendance: qualitative systematic review and meta-synthesis. Clin Rehabil. 2013;27(10):948–59.
32. Ware J, Kosinski M, Bjorner J, Turner-Bowker D, Gandek B, Maruish M. Determining important differences in scores. User's Manual for the SF-36v2® Health Survey. Lincoln: QualityMetric Incorporated; 2007. p. 125–33.
33. Warkentin LM, Majumdar SR, Johnson JA, Agborsangaya CB, Rueda-Clausen CF, Sharma AM, et al. Weight loss required by the severely obese to achieve clinically important differences in health-related quality of life: two-year prospective cohort study. BMC Med. 2014;12(1):175.
34. Wiebe S, Matijevic S, Eliasziw M, Derry PA. Clinically important change in quality of life in epilepsy. J Neurol Neurosurg Psychiatry. 2002;73(2):116–20.
35. Lauche R, Langhorst J, Dobos GJ, Cramer H. Clinically meaningful differences in pain, disability and quality of life for chronic nonspecific neck pain - a reanalysis of 4 randomized controlled trials of cupping therapy. Complement Ther Med. 2013;21(4):342–7.
36. Auffinger B, Lam S, Shen J, Thaci B, Roitberg BZ. Usefulness of minimum clinically important difference for assessing patients with subaxial degenerative cervical spine disease: statistical versus substantial clinical benefit. Acta Neurochir (Wien). 2013;155(12):2345–54. discussion 2355.
37. Singhpoo K, Charerntanyarak L, Ngamroop R, Hadee N, Chantachume W, Lekbunyasin O, et al. Factors related to quality of life of stroke survivors. J Stroke Cerebrovasc Dis. 2012;21(8):776–81.
38. Turpin KV, Carroll LJ, Cassidy JD, Hader WJ. Deterioration in the health-related quality of life of persons with multiple sclerosis: the possible warning signs. Mult Scler. 2007;13(8):1038–45.
39. Gross DP, Algarni FS, Niemelainen R. Reference Values for the SF-36 in Canadian Injured Workers Undergoing Rehabilitation. J Occup Rehabil. 2015. 25(1):116-26.
40. Mikula P, Nagyova I, Krokavcova M, Vitkova M, Rosenberger J, Szilasiova J, et al. Coping and its importance for quality of life in patients with multiple sclerosis. Disabil Rehabil. 2014;36(9):732–6.
41. Kall LB. Psychological determinants of quality of life in patients with whiplash associated disorders-a prospective study. Disabil Rehabil. 2009;31(3):227–36.
42. Staniute M, Bunevicius A, Brozaitiene J, Bunevicius R. Relationship of health-related quality of life with fatigue and exercise capacity in patients with coronary artery disease. Eur J Cardiovasc Nurs. 2014;13(4):338–44.
43. Tersteeg IM, Koopman FS, Stolwijk-Swüste JM, Beelen A, Nollet F, CARPA Study Group. A 5-year longitudinal study of fatigue in patients with late-onset sequelae of poliomyelitis. Arch Phys Med Rehabil. 2011;92(6):899–904.
44. Brusse E, Brusse-Keizer MG, Duivenvoorden HJ, van Swieten JC. Fatigue in spinocerebellar ataxia: patient self-assessment of an early and disabling symptom. Neurology. 2011;76(11):953–9.
45. Boosman H, Visser-Meily JM, Meijer JW, Elsinga A, Post MW. Evaluation of change in fatigue, self-efficacy and health-related quality of life, after a group educational intervention programme for persons with neuromuscular diseases or multiple sclerosis: a pilot study. Disabil Rehabil. 2011;33(8):690–6.
46. Sprott H. What can rehabilitation interventions achieve in patients with primary fibromyalgia? Curr Opin Rheumatol. 2003;15(2):145–50.
47. Tseng SH, Chen HC, Tam KW. Systematic review and meta-analysis of the effect of equine assisted activities and therapies on gross motor outcome in children with cerebral palsy. Disabil Rehabil. 2013;35(2):89–99.
48. Farivar SS, Cunningham WE, Hays RD. Correlated physical and mental health summary scores for the SF-36 and SF-12 Health Survey, V.I. Health Qual Life Outcomes. 2007;5:54.
49. Hopman WM, Harrison MB, Coo H, Friedberg E, Buchanan M, VanDenKerkhof EG. Associations between chronic disease, age and physical and mental health status. Chronic Dis Can. 2009;29(3):108–16.
50. Whynes DK, McCahon RA, Ravenscroft A, Hodgkinson V, Evley R, Hardman JG. Responsiveness of the EQ-5D health-related quality-of-life instrument in assessing low back pain. Value Health. 2013;16(1):124–32.
51. Khanna D, Tsevat J. Health-related quality of life–an introduction. Am J Manag Care. 2007;13 Suppl 9:S218–23.

III