# What fits me?

# "Tailoring" tricycles for people with disabilities, with activity and participation as goals.

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# **Doctoral Thesis**

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## **ABSTRACT**

#### **Purpose**

To promote increased activity, experience of mastery and participation for people with disabilities by "tailoring" tricycles to each individual. This study explored whether specific tests can predict the most optimal tricycle type. In addition, it generated knowledge about relevant factors for tricycle choice and use, and investigated cycling outcomes and general activity levels after the procurement of an individually adapted tricycle.

#### Research design

Observational study with people with disabilities as participants.

#### Methods

Children, youth and adults planning to apply for a tricycle as an assistive device for physical disability, during a stay at a rehabilitation centre or via a therapist in their municipality, were invited to participate. The 6-Minute Walk Test, the Trunk Impairment Scale, the 30-Second Sit-to-Stand Test, the Oxford Scale of muscle strength and range of motion testing were used to determine the most appropriate test for predicting the best fitting tricycle type for each individual. In addition, power (watt) when pedalling was measured. Participants also answered questions about important factors when choosing a tricycle as well as their amount of cycling, cycling performance, satisfaction and where and with whom they cycled via an online questionnaire. General activity levels before and after the participants received their tricycles were measured using an accelerometer. The Statistical Package for the Social Sciences (SPSS) was used to record and analyse data. Descriptive analyses, cross-analyses and parametric and nonparametric tests were used based on the relevance, type and distribution of data.

#### Results

In total, the study included 50 participants with a large variety of complex disabilities, who ranged in age from 5 to 79 years. Almost half of the participants (46%) were men. The participants applied for nine different adapted tricycles. None of the included tests could alone predict tricycle type. Safety, comfort and mastery were revealed as important factors for tricycle choice, and 94% of the participants used their tricycle. Obtaining a tricycle led to a significant increase in cycling frequency, performance and satisfaction. Those applying

during a rehabilitation stay (n = 30) reported the highest cycling performance and satisfaction with cycling. General activity level measurements showed both large increases and decreases from pre- to post-test, but at a group level, no significant change was found. Reported reasons for tricycle use were joy, the feeling of freedom and increased mobility, whereas reasons for little use were insecurity, pain and bad weather conditions.

#### Conclusion

Large variations in personal characteristics and needs indicate that individual assessments and adaptations are necessary to find the most appropriate tricycle. Participants who received a tricycle used it and were satisfied when cycling. However, the acquisition of a tricycle did not necessarily lead to an increased general activity level. Efforts should be made to find and address activity barriers so more people with disabilities can experience mastery and participation.

#### Keywords

Assistive device for physical activity, tricycle, disability, participation, International Classification of Functioning, Disability and Health (ICF), the Family of Participation-Related Constructs (fPRC), Adapted Physical Activity (APA)

## **OPPSUMMERING**

#### Hensikt

Å fremme økt aktivitet, mestringsopplevelse og deltagelse for personer med nedsatt funksjonsevne, ved å «skreddersy» trehjulssykkel til den enkelte. Studien undersøkte om spesifikke tester kan forutsi hva som er den best egnede trehjulssykkelen. I tillegg genererte den kunnskap om relevante faktorer for valg og bruk av trehjulssykkel, samt undersøkte eventuelle endringer i sykkel-resultater og generelt aktivitetsnivå etter anskaffelse av en individuelt tilpasset trehjulssykkel.

#### Forskningsdesign

Observasjons-studie med personer med funksjonsnedsettelser som deltagere.

#### Metoder

Barn, unge og voksne som planla å søke om aktivitetshjelpemiddelet trehjulssykkel, under opphold på et rehabiliteringssenter eller via terapeut i sin hjemkommune, ble invitert til å delta. Trunk Impairment Scale, 6-minutters gangtest, 30 sek. sitte og reise seg-test, Oxford skala for muskelstyrke og bevegelsesutslag ble målt for å undersøke om én eller flere av testene kunne predikere den best egnede trehjulssykkel-typen for den enkelte. I tillegg ble kraftbruk ved sykling målt med wattpedaler. Deltakerne svarte også på spørsmål om viktige faktorer for valg av trehjulssykkel. Mengde sykling, sykkelferdighet og -tilfredshet, samt hvor og med hvem de syklet ble undersøkt med et nettbasert spørreskjema. Generelt aktivitetsnivå før og etter at deltakerne fikk trehjulssykkelen ble målt ved hjelp av et akselerometer. The Statistical Package for the Social Sciences (SPSS) ble brukt til å registrere og analysere data. Deskriptive analyser, kryssanalyser, parametriske og ikke-parametriske tester ble brukt basert på relevans, type og distribusjon av data.

#### Resultater

Totalt inkluderte studien 50 deltagere i alderen 5 til 79 år, med stor variasjon av diagnoser og funksjonsnivå. Nesten halvparten av deltagerne (46 %) var menn. Deltagerne søkte på ni forskjellige typer trehjulssykler. Ingen av de inkluderte testene kunne alene forutsi best egnet type trehjulssykkel. Sikkerhet, komfort og mestring viste seg å være viktige faktorer for valg av trehjulssykkel, og 94 % av deltakerne brukte sykkelen. Å få en trehjulssykkel førte til betydelig økning i mengde sykling, sykkelferdighet og -tilfredshet. De som søkte under et

rehabiliteringsopphold (n = 30) rapporterte best sykkelferdighet og tilfredshet med sykling. Målinger av generelt aktivitetsnivå viste både stor økning og reduksjon fra pre- til posttest, men på gruppenivå ble det ikke funnet noen signifikant endring. Rapporterte årsaker til bruk av trehjulssykkel var glede, frihetsfølelse og større mulighet for å komme seg rundt. Årsaker til lite bruk var utrygghet, smerter og dårlige værforhold.

#### Konklusjon

Store variasjoner i funksjonsnivå, ferdigheter og behov tilsier at individuelle vurderinger og tilpasninger er nødvendig for å finne den mest hensiktsmessige trehjulssykkelen. Deltakere som fikk en trehjulssykkel, brukte den og var fornøyd når de syklet. Anskaffelse av en trehjulssykkel førte ikke nødvendigvis til økt generelt aktivitetsnivå. Videre arbeid bør sette søkelys på å adressere barrierene for aktivitet, slik at flere personer med funksjonsnedsettelse kan oppleve mestring og deltagelse.

#### Nøkkelord

Aktivitetshjelpemiddel, trehjulssykkel, funksjonsnedsettelse, deltagelse, Internasjonal klassifisering av funksjon, funksjonshemming og helse (ICF), the Family of Participation-Related Constructs (fPRC), tilpasset fysisk aktivitet (TFA)

# **ABBREVIATIONS**

APA Adapted Physical Activity

ATC Assistive Technology Centre

CAPE The Children's Assessment of Participation and Enjoyment

COPM The Canadian Occupational Performance Measure

CP Cerebral palsy

fPRC The Family of Participation-Related Constructs

ICF International Classification of Function, Disability and Health

ICF-CY International classification of functioning, disability and health: children and

youth version

NAV The Norwegian Labour and Welfare Administration

NIF the Norwegian Olympic and Paralympic Committee and the Confederation of

Sports

NSD The Norwegian Centre for Research Data

PAC Preferences for Activities in Children

REK The Regional Committee for Medical and Health Research Ethics

SPSS The Statistical Package for the Social Sciences

WHO World Health Organization

# **INCLUDED ARTICLES**

Article I

What fits me? Procurement of adapted tricycle for activity and participation

Berit Gjessing, Reidun Jahnsen

Disability and Rehabilitation: Assistive Technology, 2021:1-9

Article II

Acquiring a tailor-made tricycle – implications for people with disabilities

Berit Gjessing, Astrid Nyquist, Reidun Jahnsen

Technology and Disability, 2022, vol. 34, no. 1, pp. 35-44

Article III

Exploring physical activity level after procurement of adapted tricycle;

Quantity versus enjoyment.

Berit Gjessing, Astrid Nyquist, Reidun Jahnsen

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## INTRODUCTION

#### Background

In the latest decades, noncommunicable diseases, such as cerebrovascular strokes, coronary heart disease, type 2 diabetes, obesity and osteoporosis, have increased rapidly worldwide (1). Physical inactivity is, along with an unhealthy diet, the most important risk factor for such diseases (1, 2). Both the World Health Organization (WHO) and the Norwegian Directorate of Health have clear recommendations regarding the amount of physical activity to ensure health (2, 3). Specifically, the organisations recommend at least 60 minutes of moderate-to-vigorous-intensity aerobic activity each day for children. In addition, children benefit from any activity that strengthens muscles and bones at least three days a week. Experts recommend that adults perform at least 150 minutes of moderate-intensity aerobic activity or at least 75 minutes of vigorous-intensity aerobic activity weekly and two sessions a week of muscle-strengthening activities that involve major muscle groups (2, 3). In the category of aerobic activity, the WHO mentions cycling as training, a leisure activity and/or for transportation as a suitable form of activity (2).

Despite well-known recommendations, only one third of Norwegian adults meet the recommendations for physical activity levels (4). The number of people meeting the recommendations is negatively related to age, as about 50% of 15-year-olds meet them compared to approximately 90% of 6-year-olds (5). The fact that half of Norwegian 15-year-olds do not meet the recommendations for the amount of physical activity is worrying, and meeting this challenge is a national area of focus.

"Disability is part of being human" (6, p.3). Hence, people with disabilities are also encouraged to meet physical activity level recommendations. Despite criticism regarding inadequate registration of physical activity levels among people with disabilities, studies report lower activity levels among this group compared to people without disabilities (7, 8, 9, 10). Reported barriers to participation have been high demands of the activities (7), not being a member of a sports club (9) and the cost and access to facilities and adapted equipment (10). Some people with disabilities benefit from adapted activity equipment to be

able to participate in physical activity (7, 11, 12). For instance, Toovey et al. (13) found that most independently ambulant children with cerebral palsy (CP) in Australia were not able to ride a bicycle by the age of 15. These children could benefit from equipment tailored to their needs.

Possibilities for use of adapted equipment for physical activity

In Norway, people under 26 years of age with a permanent disability can apply for adapted equipment for physical activity (14). People older than 25 years of age have the same rights but must pay a co-payment of 10% (maximum NOK 5000) (15). If the application is granted, equipment is borrowed from one of the 12 Assistive Technology Centres (ATCs) at the Norwegian Labour and Welfare Administration (NAV) for as long as needed (14). This applies even if one has paid a co-payment for the adapted equipment. If one grows out of the equipment, one can apply to switch to a larger model.

NAV ATCs have lists of equipment that one can apply for in different activity categories. One should apply for the equipment at the top of the list if this is appropriate for the person and the purpose (16). If none of the equipment on the list is suitable, one can apply for another model that is not on the list. A professional assists with the assessment of which model is suitable during the testing and application process.

Individuals can access adapted activity equipment in Norway through one of two methods:

- (1) One can get assistance from a local physical or occupational therapist who contributes to the process of testing and adapting relevant equipment. Sometimes a few versions of the activity equipment can be available for testing for one session. An employee from a firm distributing the equipment may come to the local community. Sometimes, firms that provide adapted equipment or the local ATC create gatherings, where people who want to apply for adapted activity equipment can come, together with their local therapist, and try different versions of the equipment. Different models can be tested once to find the most appropriate one, after which the therapist sends an application to the NAV ATC in the person's home county.
- (2) One can get assistance from a professional at some rehabilitation centres. These centres have a wide range of equipment in each activity category, and the person

applying can test several models over one to four weeks (17). A case manager at NAV in the county where the rehabilitation centre is located processes the application.

For filmed information about how the process of procuring assistive devices for physical activity, watch this video:



Tricycles are the most common assistive device for physical activity requested in Norway (18). In 2020, 3005 leg-driven tricycles were lent out by NAV ATCs in Norway (19). The two Norwegian healthsports centres, Valnesfjord and Beitostølen, are the rehabilitation centres that apply for most assistive devices for physical activity in Norway.

#### Knowledge in the field

To get an overview of relevant research-based knowledge in the field of assistive devices for physical activity, especially tricycles, literature searches were carried out in databases such as PubMed, Embase and Pedro. Examples of search terms used in these searches were assistive devices, physical activity, leisure, disability and tricycle. Also, references used in relevant published articles were reviewed to check their relevance.

Most of the research in the assistive technology field has focused on the use of assistive equipment in general. As early as 2008, Salminen stated that limited research has been conducted in the field of assistive technology in Europe and that most research targets information and communication technology (20). Other studies described how assistive

technologies can improve individual functioning in people's everyday lives (21, 22) or emphasise the importance of assessing equipment based on each individual's goals and needs (23). Ravneberg and Söderström (24) described and discussed both the important role assistive devices play for many people to participate in society, and the possible stigma associated with the use of such equipment. They described the possibilities of technology to adapt equipment individually, even though manufacturing one product fitting many might be more socially beneficial.

Assistive devices *for physical activity* in particular have been a limited part of assistive technology research. Moreover, the studies that have been conducted have focused mostly on the use of manual wheelchairs (25, 26, 27, 28, 29). Indeed, the use of a wheelchair can lead to increased mobility and thereby increased possibilities for participation. A Swedish study reported that 41% of children with CP used a wheelchair for outdoor mobility, and that use of powered wheelchairs provided independent mobility (29). A British study found that children playing sports in wheelchairs were happy to feel mastery, be included in a fellowship and play sports like their peers (30).

The development of suitable wheelchair equipment started after World War 1, when athletes with disabilities wanted to perform more dynamic sports disciplines than what was possible at the time (25). The athletes built the first wheelchairs themselves. In the 1960s, first-generation sports wheelchairs were manufactured. The development in wheelchair technology since then has been substantial (26). Some research has been conducted on wheelchairs for use in paralympic sports or other competitive sports (27, 28), but such adapted equipment for athletes might also be beneficial for exercisers (26).

Studies from the same period, covering the use of equipment other than manual wheelchairs to assist people with disabilities to perform activities, seem limited. However, in the last five years, more research has been conducted in this field. Knowledge gaps regarding the large selection of assistive devices and how to adapt each piece of equipment have been exposed by both professionals in the municipalities, who apply for assistive devices for physical activity, and ATC employees who process the applications (12, 31).

Researchers point to a lack of sufficient knowledge as a barrier to collaboration with those who can benefit from assistive devices for physical activity.

Procured assistive devices for physical activity are being appreciated and used (18, 32). Three-wheeled cycles are among the most frequently used equipment. Unlike other assistive devices, such as crutches, walkers and wheelchairs, the use of assistive devices for physical leisure time activities is voluntary and often connected to each person's activity preference (33). Individuals using such equipment in physical activity often receive positive feedback from others and report they feel valued in social activity settings. Some reported feeling less disabled when using their assistive device for physical activity than when using one for daily tasks, for instance, using a powered wheelchair for mobility (34). Reported reasons for using assistive devices for physical activity are intrinsic motivation, a well-suited area for performing the activity, having the opportunity for independent use of the equipment and being active with friends and family (11, 32). Some use such equipment for transport or for the possibility to be outdoors, while others use it to be physically and/or socially active (34).

A British study explored children's experiences with adapted cycling (35). Children with CP aged 2-17 years could borrow a bicycle or tricycle for several sessions over six weeks. The children reported positive experiences of learning a new skill and having the opportunity to participate in an activity with friends and family. The researchers recommended cycling as a relevant part to rehabilitation programmes, and encouraged physiotherapists to consider this possibility in their meetings with people with disabilities (36).

#### Importance of the present study

Since people with disabilities are less physically active than recommended (8, 9, 10), it is important to explore possible ways to increase activity and participation. This is especially important for children, youth and young adults, as a physically active lifestyle when young is associated with having a physically active lifestyle later in life (7, 37). Waltersson and Rodby-Bousquet found that being physically active as an adolescent with CP doubled the probability of being active as an adult (38). Moreover, intrinsic motivation has been shown to promote persistent activity (39). Therefore, it seemed crucial to direct this research towards enabling

physical activity that motivates people with disabilities. This is not only a matter concerning those engaged in sports and outdoor life, but also professionals in the field of re-/habilitation.

An available assistive device is a facilitator for physical activity (40, 41). Although some research has been conducted over the last five years on assistive devices for leisure time activities, knowledge gaps remain. Since tricycles are the most used assistive device for physical activity in Norway, it seemed natural to focus the research on this particular type of equipment, with the hope that this research can facilitate research on other assistive devices for physical activity.

Since the Norwegian system of accessing tricycles is partly based on predetermined types of tricycles, it seems relevant to explore whether this system leads to increased activity and participation. For instance, for the sport para-rowing, individual adaptation of the equipment (adjustment of the seat) led to an increased power output of almost 50% (42). Could adjustments to a tricycle or a change of tricycle type lead to a similar increase in power output? If so, does it affect the cyclist's experience of, and motivation for, the cycling activity?

The anticipated outcome of this study was that people with disabilities, with an adapted tricycle, would be motivated to be regularly physically active. Further, this research adds to the discussion of whether the Norwegian system of procuring assistive devices for physical activity, specifically tricycles, is optimally organised.

#### Thesis aims

## Main goal

To promote increased activity, experiences of mastery and participation for people with disabilities by "tailoring" tricycles to each individual.

#### Subgoals

The subgoals, which contribute to achieving the main goal, are shown in Figure 1. Since subgoal 4 and 5 are results of subgoals 1-3, they are presented in boxes, so that the connection between the subgoals is more visual.

3. Investigate if acquiring Explore whether specific Generate knowledge about a tricycle leads to tests can predict which important factors for better cycling tricycle type fits best to tricycle choice and for outcomes and which individual tricycle use increased activity level (paper I). (papers I and III). (papers II and III). Use new knowledge from sub-goals 1-3 to suggest more accurate methods for testing and adapting tricycles to people with disabilities. Communicate knowledge from sub-goal 4 to professionals whose task is to contribute to the testing and adaptation of tricycles in the specialist and municipal health services, as well as to those who benefit from cycling with a tricycle.

**Figure 1:** The subgoals of the study.

## Definitions of key terms

#### Disability

"The outcome of the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome or depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports)" (43, p. 12).

# Person with disability

"Those who have 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'" (43, p. 12).

# Activity

"The execution of a task or an action by an individual" (44, p. 10).

#### **Participation**

"Involvement in a life situation" (44, p. 10).

#### Mastery

"Mastery is a psychological resource that is conceptualised as the extent one perceives a sense of control over important life outcomes and is a predictor of emotional well-being" (45).

## Tricycles

In this study, tricycles refer to assistive activity equipment that people with permanent disabilities could apply for through their NAV ATC during the research period. Tricycles included in the study are shown in Figure 2.



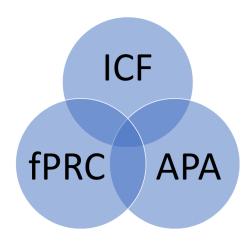
Figure 2: Overview of the nine included tricycle types.

## THEORETICAL FRAMEWORKS

In the following, three theoretical frameworks will be presented:

- 1) The International Classification of Functioning, Disability and Health (ICF),
- 2) The Family of Participation-Related Constructs (fPRC),
- 3) Adapted Physical Activity (APA).

Although all three frameworks are independent, the fPRC and APA elaborate the description of the "activity" and "participation" domains in the ICF.



**ICF** 

**Figure 3:** Three mutually dependent frameworks: The International Classification of Functioning, Disability and Health (ICF); The Family of Participation-Related Constructs (fPRC); Adapted Physical Activity (APA).

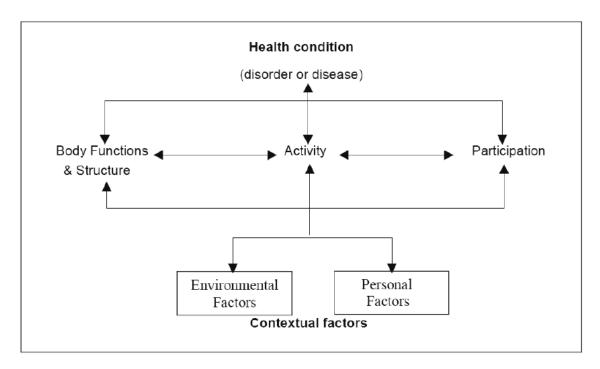
# The International Classification of Functioning, Disability and Health

Up until the latest parts of the 20<sup>th</sup> century, health, function and disability were understood using a medical model, under which disability was seen as a result of impairment of body functions or structures that should be

fixed or normalised (46). Disability was seen to be caused by disease or trauma and was the problem of the person (44, p. 20). Accordingly, individually directed medical care given by professionals was considered the primary solution.

Towards the end of the 20<sup>th</sup> century, a shift occurred toward the social model, which conceptualised that society should facilitate optimal function for everybody, regardless of body functions (47). The limitation was not understood to belong to the individual, but was a result of deficient environmental modifications (44, p. 20). Any impairment was viewed as mainly a socially created problem that required a social solution. The goal of the social model was a universal design and full inclusion of all human beings into a social society.

During the last 20 years, another shift has occurred toward a relational model, which conceptualises health, function and disability within interactions. In other words, both a person's body function and structures and their environment can affect functional level and health. The WHO worked to develop a framework and classification to capture these dimensions, and published the ICF in 2001 (44). ICF is meant to provide a coherent understanding of different perspectives of health from both a biological, environmental and personal perspective (44, p. 20). The WHO states that the ICF was meant to shift from a focus on where a disability began and where health ended, to a focus on degrees of health and functioning in society (48). A diagnosis alone cannot describe the functional level or need for health services. For instance, the diagnosis of CP does not describe a person's level of disability or functioning, as the diagnosis covers gross motor function levels from those who can walk, run and jump to those who have no independent mobility (49). The ICF describes levels of functioning and disability that can be used across national borders. In the ICF, disability and functioning are outcomes of interactions between health conditions and contextual factors. Figure 4 presents the model describing the interaction between these health conditions and contextual factors as well as the components "Body Functions & Structure", "Activity" and "Participation".



**Figure 4:** Interactions between the components of the International Classification of Functioning, Disability and Health (ICF) (44, p. 18).

The components are defined as follows: *body functions* refer to "physiological functions of body systems", *body structures* are the "anatomical parts of the body", *activity* refers to "the execution of a task or action by an individual", *participation* is "involvement in a life situation" and *environmental factors* are "the physical, social and attitudinal environment in which people live and conduct their lives" (44, p. 10). The component *personal factors* is not defined the same way as the others, but includes gender, age, social background, experience and coping styles (44, p. 17). Such factors influence how each individual experiences disability.

Qualifiers in the ICF are codes that specify the level of individual functioning in the given components (44, p. 10). The *activities* and *participation* components have two qualifiers: capacity and performance (44, p. 127). Capacity is the highest level of function one can reach in each domain or task and is measured in a standardised environment. Performance is what a person can do in the actual environment and is affected by environmental factors. Both capacity and performance qualifiers can be used with assistive devices. People's skills are scored based on how they perform tasks on a scale of no, mild, moderate, severe or

complete difficulty (44, p. 128). Examples of categories within *activities* and *participation* are d155 Acquiring skills, d499 Mobility, unspecified, d465 Moving around using equipment d4750 Driving human-powered transportation and d475 Driving a human-powered vehicle, such as a bicycle, tricycle, or rowboat (44, pp. 130-151).

The *environmental factors* component has facilitators and barriers as qualifiers (44, p. 223). Whether each environmental factor is a facilitator or a barrier is coded based on the effect the factor has on the function of the person whose situation is being scored (44, p. 241). Barriers are scored on a scale of no, mild, moderate, severe and complete, whereas facilitators are scored on a scale of no, mild, moderate, substantial and complete. Examples of categories within *environmental factors* are e120 Products and technology for personal indoor and outdoor mobility and transportation, e1401 Assistive products and technology for culture, recreation and sport, e2100 Land forms, e225 Climate, e310 Immediate family, e320 Friends, e355 Health professionals, e5801 Health systems and e5802 Health policies (44, pp. 181-212).

The ICF provides a solid foundation for understanding the relationship between the different components and their reciprocal impact on each other (44). In addition to the ICF, the WHO also published a children and youth version in 2007, the International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY) (50). This version is used for children and adolescents from 0 to 18 years of age, and describes more detailed body function and structures, activities, participation and environmental factors specifically relevant to this age group, including the rapid development during the first 18 years of life.

The ICF can be a useful tool to help people with disabilities engage in physical activity in their local environment. Health professionals can map the level of functioning and challenges, both at the person and societal level, as well as relevant contextual factors. Such a wide approach might be decisive for a rehabilitation programme that fits each individual. However, since the WHO introduced the ICF 20 years ago, the classification system has been criticised by various professionals (51, 52, 53). Two areas of criticism apply to the comparison of function with a norm and the unclear definition of *participation*, as it is not clear if participation represents individual activities or participating in a community (54, 55,

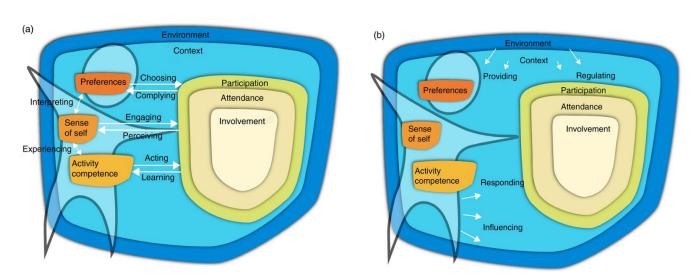
p.32). The ICF also seems to focus on objective observation of participation rather than the individual experience of participation (52, 55, p. 32, 56).

# The Family of Participation-Related Constructs

**fPCR** 

Imms et al. shared some critical views regarding the insufficient definition and description of the participation part of the ICF, and published a description of the Family of Participation-Related Constructs

(fPRC), which is a suggestion of how to see participation regarding individuals with a need for special support (51). The fPRC describes two essential components within participation: attendance and involvement. Attendance is defined as "being there" and can be measured as frequency, where and with whom. Involvement lies within attendance and is the experience of participating, including motivation, persistence, engagement and social connection. Imms et al. described two boys in a soccer game, who were both on the field, participating and attending. Yet, their involvement is quite different, as one of them is engaged in the ball and the game, while the other boy is more focused on whether his socks can be pulled up beyond his knees. The way involvement is part of attendance is shown on the right side of Figures 5a and 5b.



**Figure 5:** Family of participation-related constructs: (a) person-focused process, (b) environment-focused process (51).

A scoping review by Steinhardt et al. (56) supported Imms et al.'s description of involvement as motivation for an activity, which is not necessarily observable. In addition, they described engagement as important in participation – as the individual's behavioural, affective and cognitive investment during performance. Involvement is described as a more stable state than engagement, which can vary more based on the setting.

Similar to the ICF, the fPRC focuses on the importance of how both personal (Fig. 5a) and environmental factors (Fig. 5b) influence, and are influenced by, participation (51). Imms et al. highlighted three personal, intrinsic factors that are important in the fPRC: *activity competence* (physical, affective and cognitive skills required to execute an activity according to an expected standard), *sense of self* (confidence, self-esteem, satisfaction and self-determination) and *preferences* (valued activities that hold meaning) (51). Researchers have posited that *activity competence*, which refers to being able to participate in one's local environment, is an essential component (12, 57). Without competence, there can be no activity. Being in an environment with a focus on adaptation and opportunities, in addition to other role models one can observe and be inspired by, has proven to help improve activity competence (11, 57).

The importance of *sense of self* was confirmed by Sæbu et al., who found that high intrinsic motivation and self-image as a physically active person correlate highly with physical activity levels (40). Bandura stated that self-efficacy (belief in own ability to manage tasks) is essential for the outcome when testing the task or activity (58). Earlier experience with the task in question will influence performance.

Concerning *preferences*, the health sector has become increasingly focused on the patient's own goals, preferences and needs (59). A Norwegian study with children and youth with disabilities, about the main facilitators for participation in leisure activities, found children's preferences were the most important facilitator, followed by enjoyment and friendship (60). King et al. (61) introduced Preferences for Activities of Children (PAC) as an instrument to map children's preferences in leisure time activities. This has been further developed and oriented more specifically to physical activities and tested in a Norwegian setting (62). In a study with 149 participants with disabilities, aged 6-17 years, the top 5-list of preferred

activities reported were swimming, going on a full-day outing, doing snow sports, doing water sports and bicycling, in-line skating or skateboarding (63).

In terms of *environmental factors*, Imms et al. (51) mentioned social and physical structures as important. The environment is described as external and affects how a person can participate. Context lies within the environment and is considered from each person's view. Context involves both other people and time as well as place, activity and objects. The context provides a frame and regulates the activity while, at the same time, individuals respond to and influence the context they are in. So, even though the activity is performed in the same place each time, the context might be different.

Environmental factors are both facilitators and barriers to participation in physical activity. Mentioned barriers include a lack of facilities (e.g. elevators or wheelchair ramps) and living in rural areas (60). Examples of environmental facilitators are universal design, available activities, available information and support from the Norwegian welfare state (e.g. leisure assistance) (40, 60). In a study examining goal attainment after a rehabilitation stay, barriers in the environment category were most frequent and described by almost two thirds of the participants (64).



## Adapted Physical Activity

Adapted Physical activity (APA) is a cross-disciplinary field of study, based on theories and methodologies from related fields, such as physical education, special education and medicine (65). APA is defined as:

a cross-disciplinary body of practical and theoretical knowledge directed toward impairments, activity limitations, and participation restrictions in physical activity. It is a service delivery profession and an academic field of study that supports an attitude of acceptance of individual differences, advocates access to active lifestyles and sport, and promotes innovative and cooperative service delivery, supports, and empowerment. Adapted physical activity includes, but is not limited to, physical

education, sport, recreation, dance, creative arts, nutrition, medicine, and rehabilitation (66).

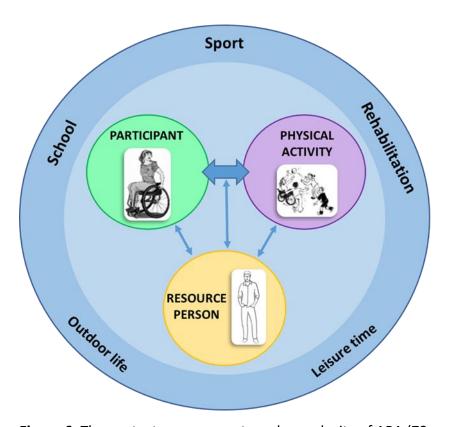
The term APA and its content has developed over the years. Before 1950, APA was connected to the correction or training of difficult-to-perform physical skills to increase function (67). However, the medical focus did not tolerate experts to consider the impact of one's environment on their function. After 1950, the focus shifted to a more service-based model that considers academic and social skills, in addition to physical skills (68). Correction of posture and increased function did not disappear, but rather a focus on participation in sports and improved fitness increased. Adapted physical education became common in the school system. Although the goal was participation and full integration into society, people with disabilities around the world were still relegated to special schools and sheltered workshops.

Then, a support-based inclusion paradigm emerged in the 1980s (69). This paradigm asserts that people with disabilities and difficulties performing certain physical skills should receive assistance to function in their natural environment and with their peers. Since 1994, APA has been stated as an umbrella term in education, recreation and sports settings (70). The term *activity* is meant to cover all formal and informal gross motor activity across the whole lifespan. Until the mid-1990s, a professional "expert" had overseen training and adaptation. Eventually, a shift occurred toward empowerment and self-determination, and individuals with disabilities were encouraged to make their own decisions regarding their learning and participation in physical activity (68). Other persons might contribute to planning, adaptation and performance, but the decision lies with each individual. The Norwegian and Danish researchers Standal, Kissow and Morisbak stated in 2007 that APA until then mainly had a treatment focus (71). They saw the need for a shift toward creating learning situations between professionals and participants, rather than traditional treatment situations. The pedagogical approach to those who perform physical activity was essential. The goal was self-determined learning, leading to activity in the participant's local community.

APA is valued as an important part of rehabilitation (72). The focus on the ability to perform play and sports in school (for children) and leisure time has benefits regarding physical

functioning, social interactions and self-esteem. A long-lasting physically active lifestyle after a period of rehabilitation has importance for the health and well-being of each individual (72).

Figure 6 is translated from Norwegian and used to describe important contexts in which APA can be performed, important components of APA and how these interact with each other (73, p. 116).



**Figure 6:** The contexts, components and complexity of APA (73, p. 116).

The outer dark blue circle represents arenas where APA takes place: outdoor life, leisure time, during rehabilitation, when performing a sport or in school. The light blue circle with the coloured circles inside illustrates the environment and the contextual conditions that form the framework for practice. The three main components in APA are the participant (green circle), the activity (purple circle) and the resource person (yellow circle), with the two first as the most essential parts. The thick two-way arrow illustrates the core of APA, namely the relationship that exists between the participant and the current activity. The thin

two-way arrows illustrate the mutual influence between actors, events and processes that take place in the composite environment. The resource person might serve as a catalyst to improve the participant's activity experience. Such a resource person might be a professional or a volunteer coach, but can also be other important persons in the participant's life, such as family members or friends.

APA is a recognised concept in Norway and is part of several research programmes, especially in the field of rehabilitation, sports and school. Rehabilitation programmes based on APA improve physical and mental functioning (74, 75, 76). Research has indicated that physical functioning was maintained after three months, while mental functioning declined in the same period. Specifically, Sæbu found positive associations between focus on self-determination in APA-based rehabilitation and changes in autonomous motivation and physical activity (77).

Several sports clubs have also succeeded in integrating APA into their activity repertoire (78). For example, the Norwegian Olympic and Paralympic Committee and the Confederation of Sports (NIF) organise all national sports federations in Norway. They have professional consultants for parasports, who can assist individuals and local sports clubs in the beginner phase. Moreover, researchers continue to search for ways to adapt sports equipment to improve athlete performance, such as designing the optimal wheelchair (26). Minimising weight and rolling resistance and optimising the design are valuable for athletes and for the mainstream wheelchair-user. Another example of adaptation in sport is when the paralympic rower, Skarstein, made adjustments to her rowing seat (42). Testing different seat angles and ensuring the necessary support of her upper body, at the same time as she got the best prerequisite for the rowing movement, led to an increased power output of 47.6%. These changes to her sports equipment gave her the opportunity of using her physical abilities more efficiently.

A study exploring experiences of participating in physical activity for people with physical and visual disabilities found that three quarters of the participants had negative experiences in physical education (79). The participants of the study reported teachers not understanding their needs, lack of sufficient adaptations and experiences of failing and not

being included. Some of these feelings were also reported by Svendby (80), who found that children with disabilities often feel that they lack sufficient physical abilities, leading to segregation. Notably, Standal and Jespersen found peers to be important when learning new wheelchair skills in a rehabilitation programme (81). Participants learned from more experienced wheelchair users, but also by testing different approaches to the different tasks, together with other participants at the same skill level as themselves.

Standal discussed whether evidence-based research, regardless of its known benefits, is the optimal research method for studying APA (82). The whole idea of APA is the unique adaptation for each individual, making controlled interventions challenging. This is supported by Røe et al. (74), who pointed out that a comparison between rehabilitation centres, with different approaches to the participants, are challenging. Overall, an APA practitioner cannot only rely on evidence-based research when meeting with a participant, but they must also consider their clinical experience (83). The more experienced the practitioner is, the larger is the "tool-box" with suggestions for adaptations that fits each individual.

# MATERIALS AND METHODS

#### Design

All three studies included in this dissertation applied an observational design. Study I consisted of people applying for an adapted tricycle during a rehabilitation stay at a healthsports centre. Study II divided the participants into two groups; those applying during a rehabilitation stay, and those applying via local therapists in the municipalities. Study III had the same participants as Study II, but did not divide them into groups.

#### Recruitment and data collection

For all three studies, participants from the age of 5 years were recruited at Beitostølen and Valnesfjord Healthsports Centres. In addition, participants were recruited from municipalities via NAV ATCs for studies II and III. The inclusion criteria were a person (a) with a disability, aged 5 years or older, (b) who planned to apply for a leg-driven tricycle (not tandem) as an adapted activity equipment and (c) fluent in Norwegian or English.

At Valnesfjord Healthsports Centre, recruitment took place during a stay specifically for testing, adapting and learning how to use a tricycle. The sports pedagogue in charge of the group was the main contributor to the recruitment process. At Beitostølen Healthsports Centre, the sport pedagogue, physiotherapist or occupational therapist who was in contact with patients planning to apply for a leg-driven tricycle reported to the main researcher. Testing of physical performance was carried out during the stay at the healthsports centres. Testing of general activity level with the accelerometer and answering the questionnaire were completed after the patient had returned home. People applying via therapists in municipalities were mainly recruited via professionals at NAV ATCs in two Norwegian counties. A few participants were recruited via therapists in the professional network of the main researcher. These were physiotherapists and occupational therapists working in municipalities. The main researcher participated in trial days arranged by NAV ATCs and firms distributing tricycles, where people who planned to apply for cycles came to test different tricycles together with their local therapist. Participants received an accelerometer to use at home and a link to the digital questionnaire.

All participants sent the accelerometer back to the main researcher by surface mail, in a prestamped envelope. Contact between pre- and post-test was maintained via e-mail. Agreement on when to wear the accelerometer and answer the questionnaire for the second time was arranged via e-mail. Accelerometers were again sent by surface mail.

This study used a sample of convenience, meaning all participants who met the inclusion criteria in the available timeframe of the recruitment period were included. Recruitment of participants and data collection started in May 2019 and ended in September 2020. Data collection continued until November 2020, because post-tests were carried out four weeks after the participants received their tricycles. Eleven participants did not receive their tricycles before the winter season, meaning those post-tests could not be done in time; thus, they were excluded from the study.

## Subjects

Following recruitment and data collection, some participants were excluded from the analysis because of a delay in bicycle delivery or incomplete measurements and/or questionnaire data, leaving a sample of 50 participants. See Table 1 for more information about these participants.

 Table 1: Sample characteristics

	Arti	Article I Article II			Article III					
	Included		Incl	Included Ex		ded	Included		Excluded	
	n = 37		n = 50		n = 20		n = 45		n = 21	
	n	%	n	%	n	%	n	%	n	%
Age (in years)										
5–10	9	24.5	12	24	3	15	9	20	6	29
11–18	10	27	10	20	3	15	10	22	2	10
19–30	8	21.5	8	16	2	10	7	16	3	14
31–50	5	13.5	8	16	6	30	8	18	4	19
51–79	5	13.5	12	24	6	30	11	24	6	29
Sex										
Female	21	57	27	54	14	70	27	60	11	52
Male	16	43	23	46	6	30	18	40	10	48
Place of residence										
City	20	54	23	46	11	55	22	49	11	52
Rural	17	46	27	54	9	45	23	51	10	48
Diagnosis										
Cerebral palsy	12	32	13	26	3	15	9	20	5	24
Intellectual disability	7	19	9	18	2	10	6	13	4	19
Neuromuscular	14	38	19	38	8	40	19	42	7	33
diseases	4	11	9	18	7	35	11	24	5	24
Others										
Application										
Healthsports centres	37	100	30	60	11	55	29	64	10	48
Local therapists	0	0	20	40	9	45	16	36	11	52

#### Outcome measures

#### Article I:

Outcome measures were chosen based on their characteristics of testing physical capacities that were considered relevant for managing cycling. These capacities were strength, endurance, balance and sufficient range of motion. The following is a list of the included tests:

- Maximum power when cycling, measured with Vector 3 watt pedals (84).
- 6-min. walk test (the distance the participants could walk on a 30 m flat floor in 6 min.) (85).
- The Trunk Impairment Scale, Norwegian version, tests dynamic sitting balance (86).
- The 30-s. sit-to-stand test (the amount of times the participants could stand up from a chair and sit down in 30 seconds) (87).
- The Oxford Scale is a manual strength test of muscles in the extremities (88).
- Range of motion test of joints in upper and lower extremities with a goniometer (89,
   90).

In addition, participants or their parents answered two open-ended questions via e-mail: What was decisive for tricycle choice, and what tricycle characteristics were important?

#### Article II:

Outcome measures were chosen based on a desire to measure cycling outcome, like frequency, performance, participation and satisfaction. Two reputable outcome measures were modified to meet this desire:

- The Children's Assessment of Participation and Enjoyment (CAPE) (61) measures diversity, intensity, with whom, where and enjoyment of 55 different activities. For this study, the CAPE was limited to cycling.
- The Canadian Occupational Performance Measure (COPM) (91) measures the importance of the activity, performance and one's satisfaction with their performance.
   The COPM was also limited to the pre-defined activity of cycling.

Both measures were collected in the same electronic Typeform questionnaire (92) and sent to the participants or their parents via e-mail.

### Article III:

Outcome measures for this study objectively measured general activity levels to capture a possible change over time. In addition to the objective measure, the study included an outcome measure to capture the participants' subjective cycling experiences. The included outcome measures were the following:

- The triaxial accelerometer ActiGraph GT3X (93). Measures steps and light, moderate and vigorous activity.
- Open-ended question in the questionnaire, mainly used in Article II, enabled the participants to provide comments regarding their cycling experience.

# Analyses

### Statistical methods

Statistical Package for the Social Sciences (SPSS) versions 25 and 27 (94) were used to analyse the findings. Descriptive analyses were conducted to reveal sample characteristics and frequencies. In Article I, cross-analyses were conducted to search for relevant associations between test results and the tricycle type applied for. Nonparametric tests were performed when skewness was found in the data, and logarithmic transformation did not give normally distributed data. Normally distributed data, through logarithmic transformation, were analysed using paired t-test. For Spearman nonparametric correlation test, the cut-point for high and moderate correlation was set at 0.7 and 0.5. The level of significance was set to a p-value of 0.05 or lower for all tests.

**Table 2:** Analyses performed in the study

Analyses	Article I	Article II	Article III
Descriptive	Х	Х	X
Spearman nonparametric correlation test	Х	X	X
Cross-analyses	Х		
Wilcoxon signed-rank test		X	
Mann-Whitney U test		X	
Paired t-test			X

# Analyses of open-ended questions

Answers to the open-ended questions were included in the study to provide a broader understanding of factors relevant to the choice of tricycles and general activity levels, beyond the quantitative data. Answers were categorised into groups based on thematic content. In Article I, answers were categorised according to participants' reasons for tricycle choice, such as safety, comfort and mastery. In Article III, the answers were divided into positive and negative comments, which were related to whether the participants had a decrease or increase in physical activity levels.

### Ethical considerations

Ethical considerations were addressed both before the project started and during the process, as this study involves both children and people with disabilities. Children are a vulnerable group, but also a group that has a right to be heard (95, Art. 12). Since children and youth must know what they are asked to take part in, they received both oral information about the study and an adapted written informed consent form (see appendix 3). Participants aged 16 and older signed their own written informed consent. Parents signed for participants 15 years of age and younger.

People with disabilities are also a vulnerable group. Understandable information is important for the participants so they can accept or decline with full knowledge of the risks and benefits of the study. The researcher talked to all the participants during the recruitment process to ensure they had the opportunity to get answers to their questions. They were also informed about the possibility to withdraw from the study at any time, without any negative consequences.

Bredahl is concerned about whether participants with disabilities in studies are treated with respect and asked to perform tasks that give meaning to them (96). Possible negative aspects of participation in this study were considered small. The test sessions did not have any negative consequences for the patients' rehabilitation stay, and only patients who should try a tricycle because of their rehabilitation goal were recruited. Also, those who answered the questionnaire did not provide feedback that it was too long or difficult. The

participants had to wear the accelerometer for one week two times, but that was neither considered nor reported to be negative. Overall, the potential advantages of the study, of better knowledge about adaptation possibilities and benefits of cycling, were considered much larger than the possible negative aspects. The positive outcomes of this study will hopefully be important, not only for the participants, but also for other people that can benefit from a tricycle as an assistive device.

A user representative with experience in applying, adapting and using a tricycle was involved from the beginning of this project. He saw the aims and the design of the study from the participants' perspectives, and ensured that relevant issues when testing, adapting and using tricycles were considered and addressed. He also conducted the tests before they were included in the study.

A description of the study was sent to The Regional Committee for Medical and Health Research Ethics (REK) in Norway for approval. They considered it to fall outside the Health Research Act because it did not collect new data about the participants' health and disease (ref.: 2018/1349). See appendix 1 for REK's full answer. Also, an application was sent to The Norwegian Centre for Research Data (NSD). They found the study to be in accordance with privacy legislation and therefore approved the study (ref.: 549301), (appendix 2). Only the main researcher had access to information about the participants' identities, and they were all pseudo-anonymised in all publications.

# RESULTS/SUMMARY OF THE ARTICLES

#### Article I

# What fits me? Procurement of adapted tricycle for activity and participation.

The purpose of the study was to identify relevant factors for people with disabilities when applying for the most appropriate adapted tricycle.

Thirty-seven people (57% women) aged from 5 to 79 years (M = 24 years, SD = 20) with various diagnoses who participated in a rehabilitation programme and applied for an adapted tricycle, completed various tests: range of motion, Oxford Scale of muscle strength, the Trunk Impairment Scale, 6-minute walk test, 30-second sit-to-stand test and power test when pedalling. In addition, they reported important factors for their choice of tricycle type.

None of the included tests could predict a specific tricycle type (out of nine different tricycles). However, all participants over 50 years applied for a recumbent tricycle, and 95% of them applied for a tricycle with an assistive motor. When the categories of tricycles with medium- and low-height seats were merged, more women applied for tricycles in this category. No men applied for tricycles with medium-height seats. As for the 6-minute walk test, 30-second sit-to-stand test, Trunk Impairment Scale and range of motion testing, a significant correlation between test results and tricycle type was not found. Overall, 60% of the participants applied for the tricycle with which they achieved the highest power output during testing.

Concerning the application process, the participants reported safety, comfort and mastery as important factors for choosing one tricycle over another. Stability when cycling and having an assistive motor with sufficient battery capacity were also reported to be important. The large selection of tricycles and the possibilities for adapting each tricycle type increased the chances of finding an appropriate tricycle for each individual. However, the variation of characteristics and needs among those applying for an adapted tricycle were challenging to the professionals who assisted in the testing and application process.

#### Article II

### Acquiring a tailor-made tricycle: Implications for people with disabilities.

This study aimed to examine whether the acquisition of an adapted tricycle led to better cycling outcomes, and if these outcomes varied depending on the application procedure.

Fifty people (54% women) aged 5 to 79 years (M = 31.5) with diverse diagnoses participated in an observational study with two cohorts: one with those applying for a tricycle via rehabilitation centres and one with those applying via local therapists. Questionnaires based on the well-established measures CAPE and COPM were distributed electronically before applying and at least three weeks after receiving their tricycle.

In total, 94% of the participants used their tricycles. Almost half cycled with their family (76% of them were children), two mostly with friends and the rest (40%) cycled mostly alone. The participants scored a median of 5 on a 5-point scale when asked how well they liked cycling, both at pre- and post-test. A significant positive change was seen regarding the participants' cycling frequency: from a median of 0 = 'once a month or less' to 2 = 'once a week'. Cycling performance and satisfaction with cycling had a significant positive change from a median of 3 to 4 on a 5-point scale.

A moderate correlation was found between how much the participants liked cycling and how often they cycled ( $r_s = 0.57$ , p < .01), whereas a high correlation was found between how much they liked cycling and how important they found the activity ( $r_s = 0.69$ , p < .01) and between assessment of performance and satisfaction ( $r_s = 0.78$ , p < .01). Participants who applied during a rehabilitation stay at a healthsports centre reported higher performance and satisfaction with cycling both at pre- and post-test (see Article II, Table 4 and Figures 4 and 5). Those applying via local therapists had a larger positive change from pre- to post-test, but did not reach the same post-test values as those applying via healthsports centres. Overall, obtaining an adapted tricycle resulted in increased cycling frequency, cycling performance and satisfaction with cycling.

Again, the large selection of tricycles and the possibilities for adapting each tricycle type increased the possibility of finding an appropriate tricycle for each individual. However, the variation of characteristics and needs among those applying for an adapted tricycle placed greater demands on the professionals contributing to the testing, adaptation and application process.

### Article III

Exploring physical activity level after procurement of adapted tricycle; Quantity versus enjoyment.

This study aimed to map which factors participants reported as important for using their tricycles in their local communities and determining whether they became more physically active.

Forty-five participants with a large variety of disabilities, aged 5 to 79 years (M = 32.3, SD = 22.7) wore an ActiGraph GT3X accelerometer for seven days at pre- and post-test. Thirty-two answered the free-text question concerning their reasons for using or not using their tricycle.

Extreme variation was found concerning changes in physical activity levels from pre- to post-test. One participant had an increase in moderate-to-vigorous-intensity activity of 104%, while another showed a reduction of 74%. Participants' results indicated a wide range of change from pre- to post-test, but no significant change was found in activity level when analysed as a whole group.

When asked about their use, 10 participants reported they did not use their tricycles because of bad weather, feeling insecure, pain during or after cycling and "did not remember that cycling was a possible activity". Reported reasons for use were mainly mobility over large distances, experiencing freedom, independence and joy (e.g., experiencing pleasure when cycling at high speeds).

Overall, the results of this study indicate that although almost everyone used their tricycles, the procurement of an adapted tricycle did not result in a consistent increase in general activity levels. Reasons for not cycling, such as feeling insecure and having pain, should be addressed by professionals so that more people can experience the benefits of a well-adapted tricycle.

# **DISCUSSION OF MAIN FINDINGS**

This chapter contains a discussion of the main findings. The discussion is not separated based on the three articles, but rather on emergent themes found among the articles. As the discussion is based on the main goal and subgoals of the project, this section begins with a summary of the main findings connected to these goals.

# Summary of main findings

The main goal of this project was to promote cycling activity and participation for people with disabilities, by "tailoring" tricycles to each individual.

Among five subgoals, the first was to explore whether specific tests could predict which tricycle type fits best to which individual. Tests performed at Beitostølen and Valnesfjord Healthsports Centres showed that none of the included specific tests could predict the most appropriate tricycle. However, age and sex did predict the tricycle category to some extent (i.e. regular or recumbent).

The second subgoal was to *generate knowledge about important factors for tricycle choice* and tricycle use. Participants reported individual considerations that ensured safety, comfort and mastery as important for tricycle choice. In total, 94% of those applying for a tailored tricycle used their bike in their local community. Hence, the goal of promoting cycling activity was reached by most participants. Moreover, high scores on how much the participants liked cycling affected their cycling frequency positively.

The third subgoal was to *investigate if acquiring a tricycle led to better cycling outcomes and increased activity levels*. Cycling performance scores increased after the participants received their adapted tricycles. They got the opportunity to participate in cycling activity with others, but many adult participants cycled mostly alone. Also, even if the cycling activity increased, the participants' general activity levels did not increase significantly on a group level.

The fourth subgoal was to use knowledge from subgoals 1-3 to suggest more accurate methods for testing and adapting tricycles for people with disabilities. Subgoal 5 was to communicate new knowledge to relevant professionals and people who can benefit from tricycle use. These two subgoals will be addressed towards the end of this thesis.

# Predicting choice

What fits whom? The heterogeneous cyclists in the equipment jungle

People with disabilities exhibit a large variety of characteristics that are not primarily dependent on diagnosis, but rather on

1. Explore whether specific tests can predict which tricycle type fits best to which individual (paper I).

function. Often, impairments in body structures and body functions (44, p. 10) lead to difficulties using regular bicycles. One example is a person with increased spasticity and/or reduced range of motion in elbows and wrists, which makes reaching the handlebars of a cycle difficult. Another example is a person with reduced balance who needs more than two wheels on their cycle.

The variety of different tricycles is not as wide as the variety of people with disabilities. However, considering all the different adjustment possibilities on each of the tricycles, with or without additional equipment, almost all can find a suitable tricycle. Due to the impairments many people with disabilities experience in body structure and body functions, adjustments can be crucial for mastering cycling. For instance, limited muscle functioning in one leg requires the adjustment of seating position and angle to the pedal, so that the precondition for muscle functioning is as optimal as possible. Adjustment on the tricycle, or change of tricycle type, might make the difference in whether one masters cycling or not (97).

Participants applied for nine different tricycles in this study. Even though Norwegian regulations restrict tricycle choice to some degree (16), the conditions for finding a suitable tricycle should be present. However, some knowledge about the selection and adjustment possibilities seems useful in the process of identifying which tricycle fits whom (98). Since many therapists complete their education without learning much about assistive devices for

physical activity, their knowledge is limited to the information they have obtained by themselves, from colleagues or by participating in courses. Thereby, knowledge among those who are supposed to contribute to the selection and adaptation process is low and random (12, 31). Experiences from this study imply that finding the optimal tricycle is more complex than performing some physical tests. Age and sex might indicate tricycle type, at least if a recumbent tricycle or a tricycle with an ordinary seat and handlebar setup is most suitable. Older people and females are more likely to end up with a recumbent tricycle than younger people and males.

In the APA model, the resource person plays an important role in uniting the participant and the chosen physical activity (73). In the process of applying for a tricycle, this resource person is usually a therapist, either working in the participant's municipality or a rehabilitation centre. The person using the tricycle might benefit from an experienced professional who can create a safe environment for testing the unfamiliar activity (73). Knowledge about adjustment possibilities on the tricycle and ways to adapt the cycling activity might be crucial for a good first experience. Later, friends and family will be important resource persons, contributing with practical assistance and motivation, which means they must also learn the activity and how to use the equipment (99).

# Choice of tricycle based on environmental factors

The APA model suggests five arenas where APA is relevant: rehabilitation, school, outdoor life, leisure time and sports (73). Cycling can be used as part of a re-/habilitation process, where the goal can be to regain or maintain physical strength or endurance. Also, in school, cycling can be an important, unifying activity. Cycling as part of transport to school, outdoor life and as a leisure time activity seems obvious. Additionally, cycling is a worldwide sport, eager to recruit more athletes. The choice of tricycle type can, and should, be based on the relevant environment, surroundings and purpose of use. The characteristics of the tricycle are likely to change if one plans to use the equipment for competition rather than riding in the neighbourhood with friends. For instance, weight is an important factor on competition equipment, while comfort, which was one of the important factors mentioned by the participants of this study, might be more important when used with friends or family in a

non-competitive cycling activity. In the ICF model, the environmental component contains both the *cycle* itself, the *surroundings* of where the cycle is used, and the *people* one (possibly) is riding with (44, p. 241).

### The tricycle

A tricycle falls under the ICF environmental factor "e120 Products and technology for personal indoor and outdoor mobility and transportation" (44, p. 181). Since environmental factors influence activity, the tricycle itself naturally affects cycling activity. The Norwegian system for lending assistive devices for physical activity contributes to the possibility for most people with disabilities to have access to a tricycle. However, the list made by NAV (100), prioritising which cycle should be tested first, might affect how well-adapted the tricycle is. Moreover, a consideration of what constitutes a satisfactorily adapted bicycle must be made. Should the cyclist be satisfied with the second-best option, as long as it is high on the list and meets the most important criteria for adjustments, or is a tailor-made tricycle necessary to perform the activity? The previous example of Skarstein's adjustment of her rowing seat (42, 101) shows that her prerequisite for optimal performance increased significantly after the adjustments. It seems reasonable to think that people with limited body functions will benefit from an optimal adjustment so that they can utilise as much of their physical potential as possible.

Therapists in rehabilitation are often concerned with training muscle strength to gain function. Thus, it can be natural to think that a tricycle without an assistive motor is the best, as long as the cyclist manages to cycle in the relevant surroundings without one. However, to be involved and keep up with family or friends, help from an assistive motor might be crucial (41). In the current study, 95% of the cyclists applied for a tricycle with an assistive motor, which should allow them to cycle longer distances and together with others.

# Surroundings

Concerning the surroundings of where the tricycle will be used, elements such as surface and slope on the road are relevant factors. For instance, does the environment contain difficult hills to ride up, which might mean an assistive motor is required? Is the road surface asphalt or gravel? Experiences from Beitostølen Healthsports Centre show that the combination of

an assistive motor on the front wheel and cycling (or especially starting) on gravel road hills, makes the front wheel spin and the cyclist does not get anywhere. The solution to this problem seems to be to have the assistive motor on the wheel(s) that carries the most weight.

### People

According to the ICF, people are also an important environmental factor. Children often start cycling with their parents and other close members of their family. When they get older, it is natural to seek company from other adults and peers (50). As seen in this study, more than half of the cyclists cycled with others and most of the children cycled with family. Since cycling is a common unorganised leisure time activity, children and youth with disabilities must have a cycle they use effectively so they can both participate in the activity and socialise with others.

Standal and Jespersen found that learning skills with peers was important during a rehabilitation stay (81). The same might be beneficial when learning to ride a tricycle. Watching peers master the same activity improves a person's self-efficacy (58). One of the factors that separates testing cycling at a rehabilitation centre from testing the same activity in one's local environment is the group setting. Support from other people with different disabilities, challenges and experiences often lead to increased motivation for pushing boundaries.

# Choice of tricycle based on personal factors

The fPRC highlights *preferences, activity competence* and *sense of self* as important to achieving participation (51). These factors are all relevant in cycling.

# Preferences

The most important considerations for the therapist before they start the application process are the person's motivation for cycling and the probability of the tricycle being used. Deci and Ryan (102) highlighted the importance of intrinsic motivation, which is described as doing something because one finds it interesting and motivating. In contrast, extrinsic motivation is doing something, such as cycling, because of a desire to achieve a specific

outcome; for instance, acceptance among peers. Mostly, applying for a tricycle is related to a cycling goal. The goal can be connected to a desire to increase physical functioning, increase activity level or participate with others. In this study, the participants were both asked about how much they liked cycling and how important cycling was to them, before applying for a tricycle. The scores were high on both questions: a median of 5 on a 5-point scale on how much they like cycling, and 4 on a 5-point scale when it comes to the importance of cycling. These numbers suggest that the people with disabilities recruited in this study had a strong preference for cycling. It is also gratifying to note that these scores were at least as high after receiving the tricycle. Hence, it seems that the participants preferred cycling. According to the fPRC, a preferred activity is a valued activity that holds meaning (51). A preferred activity also increases the chance of sustained attendance and involvement in the current activity (103).

#### Activity competence

Following Imms et al. (51), activity competence is another important factor to achieving participation. The participants' assessments of their cycling ability can be an expression of their cycling competence. The participants in this study scored their cycling performance at a median of 3 on a 5-point scale before applying for a tricycle. This number is not high, but it was likely high enough for them to believe in their skills for mastering the activity. Also, the median score rose to 4 on the same 5-point scale after a period of cycling in the participants' local environments, suggesting an even higher cycling competence and increased conditions for cycling participation.

Participants testing and learning cycling at a healthsports centre reported higher performance skills before applying for their tricycle than those who applied via a local therapist. The rationale for these numbers is somewhat uncertain, but they might partly be explained by experienced professionals contributing to the adaptation and learning process, as well as a longer time available for testing and practising cycling. Another explanation might be that those at a healthsports centre had the opportunity to learn from other cyclists with disabilities, who were learning the same activity, and with whom they could compare themselves. Bandura describes this as the Social Learning Theory, where observing and imitating others often lead to mastering new skills. (104, p. 19). Much learning occurs, both

consciously and unconsciously, when observing others performing the same skill (58). Based on one's skills and others' experiences, one chooses the most appropriate strategy for developing competence. This opportunity might be seldom present when people test tricycles and practise cycling skills in their local environment.

In addition to the physical competence of being able to use the tricycle, participation with others also requires cognitive skills, for instance to understand traffic rules and avoid dangerous situations in traffic. Such cognitive competence is also a factor that the therapist needs to consider in the application process. This might be the reason two of the participants in this study for a tandem bike. In this situation, another person is riding along and can take responsibility for ensuring their safety in traffic. Although the opportunity for participation is still present, the level of independence in the cycling activity is reduced.

# Sense of self

The third factor to achieving participation is a sense of self, including confidence, selfesteem, satisfaction and self-determination. In this study, satisfaction was scored at a median of 3 out of 5 at the pre-test and 4 out of 5 at the post-test. Since satisfaction, and thereby presumably a sense of self, increased after using the tricycle for some weeks, the participants might be more likely to sustain participation. Bandura claimed that self-efficacy, or the belief in mastering a task, is strongly connected to the previous experience with the same activity (58). Professionals, who support people with disabilities when learning to cycle, have heard stories from those with bad experiences of not mastering two-wheeled cycles. The cyclists might therefore have little self-esteem regarding mastering the activity. The first experience with another type of tricycle can be crucial for whether the person's confidence in mastery increases or decreases. Access to various tricycle models, and knowledge about the models' characteristics and about what type of tricycle fits which cyclist, are valuable in such testing and learning situations. A resource person, as described in the APA model (e.g. a therapist with knowledge and experience in the field of adapted activity equipment), can be the catalyst matching the participant with the chosen physical activity – using an assistive device. Success with the matching of person and equipment hopefully leads to an increased sense of self in connection to that specific activity.

# Factors with impact on tricycle use

# Barriers to tricycle use

Reported reasons for not using the tricycle were *bad* weather conditions, *pain* when or after cycling and *insecurity*.

2.
Generate knowledge about important factors for tricycle choice and for tricycle use (papers I and III).

### Weather

The environment in which the cycling activity takes place is part of the context, which is considered from the cyclists view and can vary from time to time (51). Several of the participants' experiences of using their tricycles were connected to weather conditions and the changing of the seasons. Participants expressed, "cycling is very weather-dependent" and "we will focus on more cycling when the weather improves". Weather perception might be influenced by earlier experiences with outdoor activities, but also by body structures and function. For example, some cyclists with disabilities might be more sensitive to the cold weather than others.

High intrinsic motivation is shown to have an impact on activity level (40), and how you perform is connected to motivation (58). The participants of this study reported high satisfaction with their cycling performance. Motivation for the activity, or cycling preference, as described in the fPRC (51), is often the basis for the application process. One can therefore assume that the participants were both motivated by the activity and able to perform the activity adequately. Still, some chose not to cycle due to what they considered to be bad weather. The APA model on page 31 presents a resource person as a catalyst for activity (73, p. 116). A resource person in these situations can be a parent, a friend or another relevant person that one can agree to cycle together with, occasionally or as a regular agreement. The threshold for skipping a cycling session is higher when you have an agreement with someone else, even if the weather is not as preferred. Further, participating in a regular cycle group might have the same positive effect on activity frequency.

#### Pain

Pain during and/or after cycling was noted by several participants as a relevant reason to refrain from cycling. The pain can be due to the movement of the body in unfavourable positions. In some cases, adjustments to the tricycle or changing to another tricycle type might cause less pain. Since some participants reported that pain can come after training, it is important to test the tricycle long enough to notice any negative consequences of use. If pain occurs, a professional might have possible solutions or adaptations that might lead to less or no pain. This is in line with APA, for which the main goal for both the professional and the athlete is to develop the best possible relationship between the athlete and the chosen activity. For instance, a professional might know about tricycles with better shock absorption that might reduce a cyclist's back pain. For another cyclist, changing the seat position might optimise joint angle in the hip, knee and ankle, resulting in less pain. In an adapting process following pain, the cyclist and the professional must investigate the reason for the pain. For instance, does the new and unfamiliar activity load lead to harmless stiffness and soreness in the muscles, or is it due to inappropriate strain on muscles, tendons or joints? Some causes should be addressed with adjustments to the tricycle, whereas others might need a gradual increase in the length of the activity for the body to adapt to the unfamiliar movement.

### Insecurity

Avoiding cycling due to insecurity is considered a personal factor and is divided into two different reasons. First, some were insecure about riding the tricycle, for instance because it was different, unfamiliar, felt unstable or was too fast. Second, others were insecure riding in traffic. These two reasons should be addressed in different ways. If the tricycle is unfamiliar, the cyclist might benefit from some more sessions with testing and extending the learning process in a safe context. If it feels unstable, the same solution might be adequate. Further, if the centre of gravity lies quite high on the tricycle, changing to another with a lower centre of gravity might reduce the cyclist's insecurity. For some, an assistive motor increases speed and insecurity. However, different motors are designed for different purposes and vary in their acceleration. Therefore, a change to a different assistive motor might help. The fPRC highlights learning and activity competence as important for attendance and involvement (51). People in this study self-reported their cycling performance. Overall, the participants reported a median of 4 on a 5-point scale, which can

be interpreted as most participants reaching a high activity competence. In contrast, scores were as low as 2 out of 5, indicating that some participants continued to experience low competence in the activity.

For participants who reported feeling insecure in traffic, practising physical skills to increase their competence might not be sufficient. Rather, guidance from others, in concrete situations and over time, might be necessary. Some might be more confident after being exposed to traffic with others. Regardless, individual considerations need to be made. Keeping people safe in traffic is an important responsibility both as a parent and as a professional. Notably, a few of the participants in this study meant to apply for a tricycle but ended up on a tandem bike, partly because of uncertainty about their ability to manage cycling in traffic alone.

# Stigma, knowledge and well-adapted equipment

Other barriers to cycling participation are described in the literature but were not highlighted by the participants. Ravneberg and Söderström (24) raised the concern that assistive devices that look different from other equipment might lead to standing out from "normality". Results from this study do not confirm this worry, as none of the participants reported feeling singled out. In contrast, Gjessing et al. (11) reported that children using assistive devices for physical activity often received comments about their "cool" equipment, suggesting that others might be jealous of their special equipment.

Other studies suggest that a lack of knowledge among professionals regarding the selection of equipment is a barrier to participation (12, 31). This finding is partly supported in this study, as participants who applied for a tricycle during a stay in a rehabilitation centre with experienced professionals reported higher cycling competence and satisfaction with cycling than those applying via their local therapist. However, we did not investigate the levels of knowledge among local therapists and their experience with such work, so we cannot assume that a lack of knowledge directly led to less cycling activity.

A lack of sufficiently adapted equipment, including tricycles, is a reported barrier to physical activity among people with disabilities (105). In the present study, no participants explicitly

expressed dissatisfaction with the adaptations that were made. As earlier mentioned, a few commented on pain while cycling, without specifying that it was due to a lack of sufficient adaptation. Bergem and Robertson reported that individuals that used well-adapted equipment reported it as a facilitator for participation (105). Because of the Norwegian system with the possibility to loan assistive devices for physical activity, most people can, in principle, access adapted tricycles. However, the amount of money connected to the scheme for those over 26 years of age may be a barrier for some people with a disability.

# Facilitators for tricycle use

Reasons for using the tricycle were reported to be *increased mobility, the feeling of freedom* and *joy*.

### *Increased mobility*

The increased mobility-facilitator meant that the participants could increase their radius for where they could move. Limitations in body functions and structure can lead to worse conditions for cycling. Lower strength in leg muscles can lead to a lowered ability to pedal to reach high speed, and lower endurance compared to people without disabilities might lead to shorter cycling distances. The possibilities for accessing adapted equipment, which can compensate for such bodily limitations, make a great difference (24). In this study, participants described having an assistive motor as beneficial because they could keep up with others and go further. Some participants even used their cars less because cycling to places covered much of their need for travelling in their local environment.

# Feeling of freedom

A feeling of freedom builds on the facilitator of increased mobility. When the participants could travel farther and at the same time be independent, they reported feeling free. Participants expressed a feeling of mastery because of their ability to do something new. Bandura claimed that when a person masters a task, it is very likely that they expect to master the same task the next time (104, p. 18). A high level of self-efficacy is an important factor for wanting to continue an activity. Experiences from Beitostølen Healthsports Centre show that many patients who master one arena report better self-esteem and are more

likely to master a skill in other arenas. Thereby, mastering cycling can lead to mastering other activities. The fPRC highlights activity competence as important for participation (51). Presumably cycling competence, both in terms of the physical ability to cycle and the cognitive ability to ride in different environments, can lead to greater attendance and involvement in cycling. This study showed that participants who tested an adapted tricycle during their rehabilitation stay scored themselves higher on cycling performance than those applying via local therapists. Following Bandura's statement about self-efficacy, it can be argued that these participants had good prerequisites for continuing with cycling activity. The feeling of mastery and freedom when trying the activity would lead them to seek out the same positive feelings in their daily life.

Results from this study show that several of the adult participants cycled mostly alone. The reasons for cycling alone rather than with others have not been further investigated. Some statements, such as "cycling gives me freedom" and "I am not dependent on anyone", suggest that they cycled alone because they enjoyed it and chose to do so.

### Joy

Feeling joy when cycling was reported to be an important factor for cycling in the participants' everyday life. Joy is closely related to fun. The word fun is one of the highlighted words of Rosenbaum and Gorter's "F-words" in child neuro-disability, which were based on the ICF model (106). They described fun as spanning the elements of personal factors and participation in the ICF model. According to the authors, the most important thing to accomplish is to ensure children have fun and that professionals listen to what the children want to do. They advise professionals against focusing on "normal" performance, but rather on helping children find their own ways to competence and confidence. The APA definition also states that it "supports an attitude of acceptance of individual differences" (66), suggesting the importance of utilising the positive qualities of each individual. Even though the high scores on the satisfaction scale after trying out tricycles during the rehabilitation stay are not a direct indication of joy in the activity, they suggest patients are more likely to continue the activity after the homecoming.

Joy can often be associated with being with other people that you like and enjoy being with. Literature supports being with others as important for use of assistive devices (11, 32, 41). The fPRC focuses on the context as important to achieving involvement in participation (51). Context can change based on which people you surround yourself with. More than half (60%) of the participants in this study used their tricycles together with others. Without asking them specifically, it can be assumed, and hoped, that they cycled with people they enjoyed spending time with.

# Better cycling outcomes – increased activity level?

# General activity level

The introduction presented a focus on general health and concern regarding reduced activity levels among people with disabilities (1, 2, 3). The introduction also implied a perception

3. Investigate if acquiring a tricycle leads to better cycling outcomes and increased activity level (papers II and III).

that a well-adapted tricycle leads to increased activity and the possibility of participating more with others, resulting in multiple health benefits. The third article presented results that do not imply a higher general activity level after receiving a well-adapted tricycle. Therefore, a straight line cannot be drawn between receiving such a tricycle and better health outcomes. However, results showed large individual differences, with some participants reporting a large increase in activity level, while others had a large decrease. One of the participants with a large increase in activity level stated, "Cycling has given me a new life". Another participant, who had a large decrease in activity level, stated the activity level decreased because "cycling is very weather-dependent". The present study did not uncover common denominators for those with a large increase or decrease in activity level. More research seems necessary so that professionals to a larger extent can assist cyclists with disabilities to be more physically active, both with and without a tricycle. This is in line with another follow-up study after rehabilitation in which patients reported improved physical and mental function, but some people maintained this improved function better than others (75). An even more individualised follow-up procedure might be necessary to support people to maintain a recommended activity level over time.

For participants with a decrease in general activity level, it is important to follow up and map the cause(s). If the cycle is not used much it is important to ask: What is the reason? Can it be addressed? The ICF model (44), the fPRC model (51) and the APA model (73) can be useful tools for identifying barriers. It can be helpful to determine if such barriers lie in body functions or structures, or if there for instance are environmental factors that can be addressed. Perhaps personal factors are the issue. For instance, perhaps focusing on increasing one's sense of self and/or activity competence is needed for them to be more active. Also, we must understand if more involvement in an activity leads to increased motivation for participation. The more precise one can be in the process of detecting the barriers to physical activity, the easier it will be to develop concrete solutions. Often, in cases where there are barriers that hinder activity, there are also some facilitators. Addressing barriers and strengthening the facilitators can contribute to more cycling activity. In this process, cooperation with a resource person can make an important difference. For instance, a professional can observe and find better adjustments on the tricycle. Further, they can provide helpful technical guidance, for instance how to make it easier to ride uphill. A friend can be a valuable resource person and bike-mate. An agreement with a friend can be decisive for carrying out a cycling session.

Cooperation between the cyclist and a professional after the tricycle is received is required. One challenge in the Norwegian system for applying and receiving adapted equipment for physical activity is that professionals applying during a rehabilitation stay are not close to the cyclist when the cycle is delivered. A local therapist is responsible for the follow-up, but this therapist might not have the required knowledge (12). Therefore, a transfer of competence between professionals is crucial. In Norway, the optimal way to ensure such competence transfer remains unclear. Over the last few years, the use of digital technology has greatly increased. Such technology might solve some of the competence transfer challenges. Digital meetings, and perhaps also meetings in a world of mixed reality, where a professional at one place can observe and guide a cyclist and another professional at another place in the country, can lead to increased knowledge among several therapists and better-adapted tricycles for the athletes.

### No increase in activity level – so then what's the point?

Concerning average physical activity levels, no increase was reported after the participants received their tricycles. Some reasons participants gave for not being more active were related to body functions, such as feeling "pain", or environmental factors, such as "bad weather". Standal discussed the challenges of measuring the effect of several interventions related to the field of APA (82). Randomised controlled trials presuppose standardised equipment and surroundings. The whole idea of APA is the "tailor-making process" for each individual (66), which leads to challenges in comparing across a group. Further, the participants might have a positive experience with cycling even though their total activity level does not increase. For instance, one participant in this study with decrease of total activity level wrote, "I love my tricycle! I have been cycling a lot the last two months".

Hopefully, most of the participants in this study had an opportunity to be active in the manner they prefer. Overall, participants reported that they liked cycling (5 out of 5 both on the pre- and post-test) and that the activity was important to them (4 out of 5 on the pretest and 4.5 out of 5 on the post-test). They also scored high on being satisfied with cycling on the post-test (4 out of 5), indicating that they were satisfied with the way they cycle. When participants like cycling, find cycling important and are satisfied with their own cycling, it is reasonable to believe that they are motivated by the activity. This motivation is also one of the most important factors for starting the application process. Intrinsic motivation is shown to be one of the most important factors for persistent activity (40). Children report fun, friendship and enjoyment as facilitators for physical activity (60). Similarly, the results of this study paint a picture of motivated participants. Less cycling than planned or desired was because of factors across all the ICF components. It seems like they appreciate the possibility they have to cycle and that they want to perform the activity. Still, it seems necessary for some of the participants to have a follow-up session with a professional to optimise the adjustments on the tricycle so that barriers to cycling, such as insecurity and pain, are reduced. Thus, even more people with disabilities can have the possibility of being active in a preferred activity in their local environment. In general, some people prioritise school or work and many prioritise time with family and friends. Others refrain from physical and social activities due to fatigue. Many people with disabilities do not have time or energy for more activity, but receiving a tricycle can give

them the possibility to do more of what they enjoy. Even though they do not necessarily become more active in general, they might be active in the way they prefer. Hopefully, they are more involved in the activity when they are active in a way they have chosen by themselves.

This discussion of the main findings focused on important factors for tricycle choice and use, cycling outcomes and consequences for general activity levels after receiving a tricycle. The next chapter presents methodological considerations.

# METHODOLOGICAL CONSIDERATIONS

### The researcher's pre-understanding

I, the PhD candidate and main researcher of this project, am an employee at Beitostølen Healthsports Centre. Experience from working with people trying to master different activities, some of them by learning how to use adapted equipment, is the foundation for my curiosity about how to ensure the best fit between equipment and people, and what possibilities such equipment can give to each individual. The professional issues that I've been involved in during everyday clinical work have formed the basis for the curiosity that has turned into research questions. I see the importance of seeking answers to these questions, so that people with disabilities can make even better use of their assistive devices. However, being so close to the research questions requires awareness about my role in the project, especially when analysing the data and discussing the results.

During the years working as a physiotherapist at the healthsports centre, with children, youth and adults, I've heard experiences from many patients who use and want to use assistive devices for physical activity, including tricycles. Stories about local barriers and facilitators, patients' experiences cooperating with local therapists and their opinions about which adjustments need to be made have coloured my view of how the system works and should work. This project is an attempt to make some of the challenges and possibilities clearer, and hopefully suggest some ideas of how to give even more people the opportunity to cycle. The years in clinical practice have shown that a tricycle, for the right person in the right context, is a tool for enjoyment and participation. During the work with this project, I've tried to ensure answers from the participants are reported as close to their original statements as possible, so that the results reflect their experiences and opinions. To ensure that the results are not only presented from my perspective, outcomes have been discussed with a user representative with personal experience of cycling, a municipally employed occupational therapist, the supervisors of the project and other professionals with experience from the field of assistive devices for physical activity.

### Design

Considering the research questions and the field of practice, an observational study was determined to be most appropriate.

# **Participants**

The sample of this study was selected based on people's wish to apply for a tricycle. This is in line with the application procedure in Norway. Including participants not interested in cycling in their everyday life would have little value and would be ethically questionable.

The sample was considered adequate to ensure sufficient strength to rely on the results. Concerning the first research question regarding a prediction of suitable tricycle types based on the results of specific tests, more participants might have led to clearer answers. However, the large diversity of people with disabilities, with their different wishes and needs, also found in the convenience sample of this study, contribute to challenges using standardised tests that are not made specifically for this purpose.

#### Data collection

For Research Question 1, the main researcher conducted all physical testing with the participants. Since the same person conducted all the tests, the chance for equal completion and scoring across participants is large. Most of the tests have well-established test protocols and clear descriptions of how to score the results (85, 86, 87). The exception is the Oxford Scale of muscle strength, as the scale might be open to individual interpretation across therapists. Still, it is a widely used test around the world (107) and was considered suitable for this study.

For Research Question 2, the data collection consisted of three open-ended questions asked in a questionnaire distributed via e-mail. The response rate was lower for these questions than for the other questions asked in the questionnaire (48.5% answered). Even though the collected data contain a variety of factors for tricycle choice and use, a response from more participants might have given a broader picture of such factors. Therefore, we might lack

some of the diversity of barriers and facilitators for tricycle choice and use. Still, there was a variation in the answers, indicating that many relevant factors were covered.

For Research Question 3, data collection was based on recognised measuring instruments – the CAPE and COPM (61, 91). Using these instruments strengthens the possibility of measuring what we wanted to measure: reported cycling frequency, participation, experienced importance, performance and satisfaction. Since cycling was the focus of this study, it was natural to exclude the 54 other activities in the CAPE, and to define the activity in the COPM as cycling. In addition to these instruments, the participants wore an accelerometer to measure their general activity levels. The specific accelerometer is widely used in other studies (108). As discussed in the article, data from the accelerometers were not suitable for comparison between participants because some wore it on their hips, whereas others wore it on their wrists. The intention for its use was to identify changes in activity levels from pre- to post-test. Thereby, analyses across the sample were not necessary.

Since the results of the study showed that capturing individual needs was necessary to find the most appropriate tricycle, and since large variations in activity level were uncovered, the research group has discussed if a design that had captured each individual's opinions and needs more accurately would have been better. Still, we might not have discovered these differences on a group level if we had not started with the current design. By focusing more on each individual, the number of participants might have been smaller, and we would have lost important information at a group level. Our chosen focus gave us relevant information, but also new questions that will be addressed in the "implications and future perspectives"-chapter.

### Statistical analytical tools

SPSS versions 25 and 27 (94) were used to analyse quantitative data. The same person who conducted the tests also conducted the analyses. Quantitative data are not as susceptible to subjective influence as qualitative data. Still, to avoid subjective influence from the main

researcher, the main supervisor contributed to the analysing process, and an independent statistician assured the quality of the analyses in the first article.

Descriptive statistics are suitable for summarising data in observational studies (109, p. 279). Such statistics were used to reveal and present sample characteristics of the data material. Parametric tests were used when data were normally distributed by using logarithmic transformation. In most of the data material, there was skewness that did not get equalised with such transformation. Therefore, nonparametric tests (i.e. Spearman's correlation test, Wilcoxon signed-rank test and Mann-Whitney U test) were used.

When analysing the results from the accelerometers, cut-off points for the different activity levels were set according to the numbers presented in Article III. Previous studies operate with different cut-off points. This is unfortunate because a comparison between studies becomes challenging. The cut-off points of this study were based on values from studies with similar samples of children and/or people with disabilities.

# Analyses of open-ended questions

The written answers to the open-ended questions provided a broader understanding of the participants' experiences, thus providing an important supplement to the statistical data by pointing out nuances that cannot be seen in tables and numbers. The researcher has tried to retain the wide range of meanings during the processing and interpretation of the answers. The three open-ended questions were analysed and categorised by the main researcher. Qualitative data are more likely to be influenced by the researcher's background and professional opinions (110, p. 60). Therefore, the research group discussed the analysing process and whether some of the statements could fit into other categories. One example is whether the statement "cycling is very weather-dependent" can be categorised as a barrier or a facilitator. In addition to the involvement of several people in the analysing process, written statements from the participants were used verbatim to ensure their opinions were represented.

# Internal validity

A constant assessment of the structure of the study and consideration of how to accurately report the results of the studied group were reflected upon throughout the study. One question that remains is whether other standardised tests could have aided in the process of finding the most suitable tricycle. The tests used in this study were chosen based on their ability to measure capacity in relevant body functions, including strength, sitting balance and endurance. Other tests not used in this study might have detected relevant physical functioning necessary for cycling more accurately. For instance, a ceiling effect was noted in the Trunk Impairment Scale. Although another test that places higher demands on sitting balance might have been more relevant, the Trunk Impairment Test was chosen because of the assumed relevance for cycling performance.

The changing seasons in Norway, combined with the time it takes from application submission to receiving the tricycle, presented some challenges. The companies that sell tricycles do not have many of each type in stock, and it can take a while from the time they get the order until they can deliver the tricycle to the cyclist. In this study, this period ranged from weeks to months. If the application was submitted late in the cycling season, the tricycle could arrive during winter. During these months, many things could have happened in the participants' lives that might have influenced the post-test results and thereby also the internal validity of the study. Other factors than the tricycle itself might have affected cycling performance and satisfaction scores. Further, habits in their lives might have changed, that affect their everyday life, and thereby their general activity level.

Quantitative data from Article II were self-reported. The researchers do not have first-hand information on how participants determined their scores. For instance, we do not know if children scored themselves or if parents or others helped them. Therefore, we cannot be sure whether the answers are the "voices" of the children using the tricycles, of an adult or a mix of both. This affects the internal validity negatively. However, short question text and smiley faces supporting the answer scale were employed to help children, and others, answer the questions without assistance as much as possible.

As discussed in Article II, answers to the question 'How often have you been cycling the last 4 months?' were biased due to artificially high scores from a large percentage of the participants who were testing tricycles during a rehabilitation stay. If these pre-test scores, reporting cycling frequency during the rehabilitation stay, are compared with post-test scores, describing cycling in the local community after receiving a tricycle, the analysis would show a decrease in cycling frequency from pre- to post-test. This decrease would appear even if the cyclist increased their cycling frequency when compared to their participation before their rehabilitation stay. Therefore, to increase internal validity, pre-scoring should ideally have been done before the rehabilitation stay. The decision to apply for a tricycle is made during the rehabilitation stay, as a result of cooperation between the patient and the professional. Since participants were recruited based on the decision to apply for a tricycle, pre-test scoring before their stay could not be done. Given this bias, little emphasis has been placed on the results of the pre-test scores and changes in cycling frequency from pre- to post-test.

# External validity

Studies are conducted so that others can benefit from the findings. This also is true for the present study. However, some aspects have to be considered regarding the transferability of these findings to other people with disabilities that want to apply for a tricycle.

Data collection was carried out from May 2019 to November 2020. During almost half of this period, the Norwegian healthcare system was affected by the COVID-19 pandemic. Professionals working with adapting and applying for tricycles, and those granting the applications, were partly unable to perform their tasks from March 2020. Participants who had applied for a tricycle before the pandemic, but received it after March 2020, might have had less follow-up from local professionals than they ideally should, for instance when it came to adjustment of the new equipment. A lack of follow-up could have led to less satisfaction with the tricycle and thereby less use. This could have affected the external validity negatively. On the other side, the pandemic did not come with national restrictions regarding outdoor life, so cycling could in theory be maintained as usual. Since other

activities, such as work, school and leisure activities in groups were paused, some might have experienced more time and opportunity to cycle.

This study took place in Norway, which is a country with a well-developed system to ensure that people with specific needs have access to assistive devices for physical activity (14, 15). This financial arrangement is unique and can lead to socioeconomic bias. Even if people in other countries find financial solutions to acquire a tricycle, they do not necessarily have the same selection of tricycle types. This can have consequences for their access to a well-adapted tricycle. In other words, the results from this study are primarily valid for Norwegians with permanent disabilities. Still, some of the results, including the description of insecurity, pain, mastery and enjoyment, can be valid for people with disabilities in other countries.

# IMPLICATIONS AND FUTURE PERSPECTIVES

Up to this point, the focus of this thesis was on subgoals 1-3. Subgoal 4 reads:

4.

Use new knowledge from sub-goals 1-3 to suggest more accurate methods for testing and adapting tricycles to people with disabilities.

This section presents a discussion of how acquired knowledge might lead to implications for practice and guidance for the future system regarding assistive devices for physical activity in general, and tricycles in particular. First, this study showed that the acquisition of an adapted tricycle led to a higher amount of cycling, better cycling performance and higher satisfaction with cycling. Such a result suggests the benefit of an adapted tricycle for the individual participant and possibly for others who meet the criteria for acquiring such an assistive device.

As the results and discussion for Research Question 1 showed, this study did not find any association between the results of specific tests and which tricycle best fits each individual. Since individual considerations are important and professional experience seems to make a difference, knowledge among those tasked with applying for an assistive device must improve. The best way to ensure better knowledge among physiotherapists and occupational therapists is to increase the focus on such knowledge in the education programmes nationally. However, even with more focus on assistive devices for physical activity in education programmes, one cannot expect all therapists to be aware of the full range of available devices, given the large selection and major developments with new products. Therefore, it might be beneficial to have national and/or regional competence centres. These centres can provide the location for testing and adapting equipment, and a place for professionals in the districts to seek knowledge when needed. This can be achieved either with a physical presence and/or via digital meeting points. For such centres to function, they are dependent on being a recognised part of the distribution system of assistive devices.

The highest satisfaction scores were reported by participants who tested tricycles at a rehabilitation centre. Results showed positive effects after introduction to tricycles during a rehabilitation stay, and these results were considered to be partly due to the learning methods used by the professionals working there. Thus, the focus of these rehabilitation institutions on the pedagogical principles of APA seems to be relevant to transfer to other learning situations elsewhere.

As discussed, one of the arguments against testing tricycles at a rehabilitation centre is that cyclists do not have the opportunity to test a relevant cycle in their environments. Local conditions are different from those at a rehabilitation centre, which may highlight other requirements for the equipment. A testing period of one or a few weeks in the applicant's local environment, as part of the application process, would ensure the equipment suits the surroundings where it is meant used.

A delay in the application process and the delivery of tricycles occurred for several participants during the data collection for this study. As motivation and skills are not necessarily long-lasting, people with disabilities should ride in their local environments as soon as possible after finding a suitable tricycle. Therefore, efforts should be made to find effective methods for the distribution of tricycles, and assistive devices in general, immediately after testing.

Most people might want their cycle to be available for use all the time, whereas others might need a tricycle for a short period or a few times each year, for instance during holidays. This might be even more true for other assistive devices, such as those for use when alpine skiing or hiking in the mountains. Therefore, an arrangement to ensure such equipment can be borrowed might be beneficial. More people can use the same equipment, and each person does not have to store space-consuming equipment in their own homes. This arrangement can work well for some types of equipment and some people with disabilities. However, equipment that requires a specific set of adjustments to fit a specific person is not ideal for such an arrangement.

While conducting this study, new questions have arisen. The first question revolves around ways to secure the application for a tricycle that fits each individual. Even though many people with disabilities obtain well-adapted equipment, they may experience greater mastery in cycling if they can optimise their physical potential. Thus, studies exploring how to gain and spread more knowledge about the adaptation process are recommended.

The second question concerns methods for mastering cycling activity. When the optimal tricycle is found, what is the optimal learning situation? Learning in the right context and with a focus on the cyclist's resources is critical. Moreover, it is important to understand if learning in a sheltered environment with experts on APA and peer learning, when the tricycle is going to be used in the local environment at home, or in the local environment without expert guidance, is best for each individual. Some research points out the benefits of learning in a group setting with peers and professional guidance (63, 64, 111, 112). The feeling of freedom and safety to challenge themselves, at the same time as receiving support from others in a similar situation, motivates learning new skills. However, more knowledge is needed about appropriate methods of transferring newly acquired skills to further activity and increased participation in individual environments.

The third question relates to how people with disabilities can increase their general activity levels. Cycling seems to be part of the solution for some, but not for all. What motivates those who did not increase their general activity levels after acquiring a tricycle? What barriers do they meet, and how can they be addressed?

### Subgoal 5 reads:

Communicate knowledge from sub-goal 4 to professionals whose task is to contribute to the testing and adaptation of tricycles in the specialist and municipal health services, as well as to those who benefit from cycling with a tricycle.

The three articles and this thesis are the beginning of the communication of knowledge from this study. Also, results have been presented and will continue to be presented at relevant conferences in various professional settings. Plans to disseminate knowledge via other

channels, such as national professional journals, journals by and for people with different diagnoses, newspaper articles and digital newsletters, are in place. People in the project resource group, including a user representative and an occupational therapist working in a municipality, will contribute to this process. Focus areas that will be communicated are the following:

- The activity possibilities that lie in the "equipment jungle" of tricycles.
- The need to consider individual characteristics.
- The need for professional competence.
- The benefits from the possibility of being able to participate with others.

## SCIENTIFIC IMPACT AND CLINICAL RELEVANCE

This thesis contributes to new knowledge in a field of science that still has several knowledge gaps. It brings us closer to understanding the complexity of tricycles as assistive devices for physical activity. At the same time, it describes the benefits that the participants experience when they get the opportunity of being active in a new way. This study focuses on the importance of specialist competence that might be used as a "voice" to improve knowledge dissemination. Most importantly, it sheds light on the importance of activity and participation for people with disabilities, and it describes the satisfaction and feeling of mastery that many people experience when they get the opportunity to use a "tailor-made" tricycle.

## CONCLUSION

The main goal of this study was to "promote increased activity, the experience of mastery and participation for people with disabilities by 'tailoring' tricycles to each individual". Results show that the participants of this study did not increase their general activity level, although large individual differences were reported. Participants reported high levels of mastery when using tricycles, and over half of the participants used their tricycles mostly together with others.

Results from subgoals 1-3 lead to increased knowledge about the main goal of this study. The first subgoal was to "explore whether a specific test can predict which tricycle type fits best to each individual". Results indicate that finding a suitable tricycle is about navigating in an equipment jungle. The possibilities are many, but cyclists are heterogenous and no single test can identify the ideal tricycle. Individual considerations are crucial and experienced professionals might play an important role during the trial period. Dissemination of knowledge to local stakeholders will therefore be important, as knowledge translation will contribute to more people with disabilities get a tailor-made tricycle or other assistive devices for active participation.

The second subgoal was to "generate knowledge about important factors for tricycle choice and for tricycle use". Both personal factors and environmental factors play a role in whether the possibility for participation is present and the cycling activity is a success. Safety, comfort and mastery were considered important for tricycle choice and use.

The third subgoal of this study was to "investigate if acquiring a tricycle leads to better cycling outcomes and increased activity level". Even with a well-adapted tricycle and high scores on cycling performance and satisfaction with cycling, as a group, the participants did not increase their general activity levels. Still, 94% of the participants used their tricycles in their local community. Reasons for low activity levels are diverse, and measures to contribute to an increased amount of activity will be different in each situation. It is important to notice that many participants did increase their general activity levels

significantly. For those individuals, the tricycle meant they found a new arena for activity and participation. Further, some of those who did not increase their general activity levels found a way of being active that they enjoyed. They expressed motivation for cycling and satisfaction with the activity, which is beneficial for people's health and well-being.

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## ARTICLE

What fits me?

Procurement of adapted tricycle for activity and participation



## ORIGINAL RESEARCH 3 OPEN

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## What fits me? Procurement of adapted tricycle for activity and participation

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#### **ABSTRACT**

**Purpose:** To determine which factors are relevant when applying for the most appropriate adapted tricycle for people with disabilities.

**Methods:** Patients participating in a rehabilitation programme and planning to apply for an adapted tricycle were invited to participate in an observational study. Measurements used were watts when pedalling, 6-minute walk test, the Trunk Impairment Scale, 30 s sit-to-stand test, Oxford Scale of muscle strength and range of motion testing. Participants answered questions about important factors for choice of tricycle. Nonparametric correlation tests were performed using SPSS to investigate relevant associations between test results and tricycle type.

**Results:** The study included 37 participants with a large variety of complex disabilities who applied for 9 different adapted tricycles. Participants ranged in age from 5 to 79 years (M = 24 years, SD = 20), with almost half (49%) under 18 years of age. More than half of the participants (57%) were women. Most participants chose an assistive motor. Participants over 50 years applied for a recumbent tricycle. Answers on questionnaire revealed safety, comfort and mastery as important factors for tricycle choice.

**Conclusions:** Large variations in personal characteristics and needs indicate that individually tailored assessments are necessary to find the most appropriate tricycle.

#### > IMPLICATIONS FOR REHABILITATION

- Large variations of characteristics and needs among people with disabilities and tricycle types indicate individual-level analyses are necessary to find the most appropriate one.
- A large selection of tricycles and support from an experienced professional when testing are success factors for finding the most appropriate tricycle.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Rehabilitation; participation; tricycle; adapted physical activity; adapted equipment; assistive technology

## Introduction

any way.

Children, youth and adults benefit from regular physical activity [1–4]. Despite clear national and international recommendations for a physically active lifestyle [1,2,5], people with physical disabilities are far less active than people without disabilities [6,7]. To meet physical activity recommendations, people must find an activity they enjoy [1].

Some people with physical disabilities are prevented from using ordinary activity equipment, such as skis and bikes, but can benefit greatly from adapted activity equipment, including special bikes [7,8]. Such equipment is quite accessible in Norway. Children and youth with significantly reduced function can, with help from a physiotherapist or an occupational therapist, apply for assistive activity equipment [9]. People over 26 years of age must pay a co-payment of 10% or up to NOK 4000 [GBP 350] [10], but funding is limited for this age group and does not meet current demand. If granted, people can borrow equipment from the Norwegian Labour and Welfare Administration (NAV) for as long as they need.

Some research has considered the benefits of using assistive equipment/technology in general [11–15]. However, the lack of

information about available assistive equipment is one weakness in the provisioning process [16]. Little research has been conducted in the field of adapted equipment for physical activity [17–20], and no research is found on the procurement of adapted bikes specifically. In this study, a tricycle is the chosen adapted equipment, both because cycling is a very common and useful activity in the general population, and because it is expected that almost everyone can participate. Tricycles are also the most common adapted equipment for activity in Norway [21], and cycling can compensate for reduced walking function among many people with a physical disability. Since each tricycles are tested and adapted to each individual (e.g., with specialized pedals and handlebars, and support for the upper body), we refer to the tricycles as "adapted." The adaptation makes it possible for the individuals to make the best out of their limited physical function.

In this article, we use the International Classification of Functioning, Disability and Health's (ICF) definition of activity as "the execution of a task or action by an individual" and participation as "involvement in a life situation" [21]. We are also particularly concerned about the *involvement* part of participation, which refers to the subjective experience of participation that might

include motivation, engagement, persistence and social connection [22].

The project referred to in this article was carried out at Beitostølen and Valnesfjord Healthsports Centres, which are (re)habilitation centres offering secondary rehabilitation to persons with disabilities [23]. The rehabilitation programme is based on the theoretical framework of adapted physical activity [24, p. 85], meaning the activity is adapted to each unique person's preferences, goals and needs [25]. Adaptation of an activity may include individual instruction, adaptation of environmental factors and, in guite a few cases, the use of assistive devices. Even though the variety of assistive devices is large, the variety of persons using such equipment is even larger. Therefore, the most suitable standardized equipment might need to be tailor-made to each individual. Even Paralympic athletes benefit from individually adapted assistive devices in order to utilize their resources in the best possible way [26]. The people participating in the rehabilitation programs at the Healthsports Centres usually do not have Paralympic ambitions, but they still need individual adaptation of the equipment for optimal performance and thereby experience of mastery. Therefore, a range of assistive devices for activity, in this study tricycles, are available for testing at the Healthsports Centres. At Beitostølen Healthsports Centre, a parents' programme and courses for local service providers are also offered to enhance the transfer of new skills to enable participation in activities in the local community [27]. The vision at the centre is "activity and participation throughout life" [28], and the philosophy of the (re)habilitation program is to ensure transfer and continued physical activity in the participants' local environment.

Norway has good support arrangements for obtaining assistive activity equipment and the individualized adaptation is integrated in the assessment and trial process. Still, large variations are seen in how tricycles are chosen and individually adapted and how accurate and tailor-made the adjustments are. Therefore, this study aimed to determine whether specific standardized tests can help therapists and people with disabilities choose the most appropriate adaptive tricycle. A second aim, was to map the participants' subjective reason for choosing a tricycle, and what characteristics of the tricycle were decisive for their choice.

The Regional Medical Committee for Research Ethics in Norway determined the study fell outside the Health Research Act, and, thus, did not need their approval (ref.: 2018/1349). The Norwegian Centre for Research Data approved the study (ref.: 549301). The identity of the subjects is anonymous in this article.

## **Materials and methods**

## Desian

The present study applied an observational design.

## Participants and inclusion procedures

Participants with disabilities were recruited from Beitostølen and Valnesfjord Healthsports Centres. Inclusion criteria were people who:

- planned to apply for a leg-driven tricycle in order to follow up cycling in their local environment
- understood Norwegian or English
- were able to cooperate with the first author during testing.

Inclusion was independent of age and diagnosis, but the Healthsports Centres do not provide (re)habilitation programmes for children younger than 5 years. Professionals at the Healthsports Centres recruited participants, while the main author informed them about what participation would entail. Participants above 16 years of age provided written informed consent, whereas parents signed for participants below 16 years of age. The participants' diagnostic and demographic data (age, gender and place of residence) were obtained from their medical records or orally from the participants.

#### Outcome measures and data collection

The standardized tests were selected based on physical characteristics deemed important for bicycle selection, such as strength, endurance, balance and range of motion. They were conducted by the professionals at the Healthsports Centres. The selection of tricycles consisted of 12 different types. Participants tried two or three of these, based on which ones the participant and professional considered most appropriate.

One test was conducted during tricycle testing:

Vector 3 watt pedals [29] were put on all tricycles during testing, to measure approximate (margin of error ± 1%) maximum power when cycling. Maximum watt scores were used as output scores. A high score indicated the opportunity to create great power in the sitting position of the tricycle in use, and was considered to be positive. Testing of tricycles was conducted on a 400 m flat asphalt pavement (one round per tricycle). Participants tested at least two different tricycles. Two participants tested three tricycles, since the first two did not fit satisfactorily.

Five tests were conducted separately from cycle testing:

- 6-min walk test [30] tests the distance a person can walk in 6 min on a 30 m flat floor. This test is suitable for measuring endurance and shows good internal consistency. However, the test might show a ceiling effect for people with normal exercise capacity. It was included in the study to determine if the test could separate those who need an assistive motor from those who do not.
- The Trunk Impairment Scale, Norwegian version [31] assesses dynamic sitting balance. Total score ranges from 0 (minimal performance) to 16 (perfect performance). This test shows good construct validity, excellent internal consistency and high inter-tester reliability. The test was included in an attempt to separate those who need a low seat with a backrest from those who do not.
- The 30-s sit-to-stand test [32] measures lower body power and strength by testing how many times the subject can sit down and stand up in 30 seconds. Although the tool shows good internal consistency, it might have a ceiling effect [30]. This test was included given its ability to measure strength and because the test requires balance skills.
- Manual strength test of lower extremity muscle groups with the Oxford Scale [33]. Scale from 0 (paralysis) to 5 (normal). This test is frequently used in clinical practice and shows acceptable specificity, but does not detect accurate muscle weakness [34]. The test was included because of the assumption that muscle power is relevant when choosing a tricycle. Muscle groups tested were dorsal and plantar flexors of the ankle joints, knee flexors, knee extensors, hip flexors and hip extensors.
- Range of motion was measured with a goniometer, which is shown to be acceptably reliable [35,36]. The tests were included because of the assumption that the range of motion will affect possible sitting positions and/or need for handlebar close to the body, and thereby tricycle choice. Joints tested and cut off-points for reduced range of motion were:



hip flexion 120°, hip extension 10°, knee flexion 140°, knee extension 10°, ankle dorsiflexion with hip and knee in 90° flexion 20°, ankle plantar flexion with hip and knee in  $90^{\circ}$ flexion 45°, elbow extension 0°, wrist flexion 80° and wrist extension 70°.

After the participants had received their tricycles, they, or their parents, answered a questionnaire with two open-ended questions via e-mail: (1) What was decisive for choosing the exact tricycle that was applied for? and (2) What characteristics of the tricycle are important to you?

Data were collected between May 2019 and November 2020.

## Statistical analyses

Results were recorded and analyzed using SPSS version 25 (SPSS Inc., Chicago, IL). Descriptive analyses were conducted to reveal frequencies and sample characteristics. Cross-analyses were performed to find relevant associations between test results and tricycle type. Nonparametric correlation tests were performed to determine factors that could predict tricycle choice. Moreover, each test result was analyzed separately to investigate whether the specific test could predict the most appropriate tricycle choice.

#### **Results**

## **Participants**

The sample was composed of 37 participants who applied for an adapted tricycle. The participants ranged in age from 5 to 79 years (M = 24 years, SD = 20), of which 18 (49%) were under 18 years of age. More than half of the sample were women (n = 21, 57%). The participants presented a large variety of complex disabilities, including neurological, neuromuscular diseases, Down syndrome and rare syndromes (Table 1).

Table 1. Sample characteristics.

Category	n	%
Age (in years)		
5–10	9	24.5
11–18	10	27
19–30	8	21.5
31–50	5	13.5
51–79	5	13.5
Gender		
Female	21	57
Male	16	43
Place of residence		
City	20	54
Rural	17	46
Diagnosis		
Cerebral palsy	12	32
Intellectual disability	7	19
Neuromuscular diseases	14	38
Others	4	11

#### Tricycles

The participants applied for nine different tricycles that could be divided into three different categories:

- Three tricycles (Sunny (n=5), Medema (n=1) and Victoria (n=1)) with a high seat (> 70 cm for adults) and ordinary handlebars. Two wheels at the back or front.
- One tricycle (Easy Rider (n=9)) with lower (medium) seat (57–63 cm for adults) with backrest. Two wheels at the back.
- Five recumbent tricycles (Kettweisel Heinzmann (n = 13), Gekko (n=4), Scorpion (n=2), Lepus (n=1) and Azub (n = 1)) with a low seat (< 57 cm), backrest and alternative handlebar beside the thighs. Two wheels at the back or front.

All tricycles can have an assistive motor if needed, and only two of the participants applied for a tricycle without an assistive motor. The three types of tricycles are shown in Figure 1. The corresponding colours are used in subsequent figures for ease of identification.

#### **Outcomes**

Spearman's nonparametric correlation test showed a few weak correlations between personal characteristics and bike type. Higher age ( $r_s = 0.47$ , p = .004) and longer distance achieved during the 6-min walk test ( $r_s = 0.33$ , p = .047) were correlated with applying for a tricycle with a lower seat. The same relationship was seen for women ( $r_s = 0.414$ , p = .011), but only when the tricycles were divided into two categories: high and low (with medium and low in the same category). With these two categories, a correlation was found between higher scores on the 30-s sit-to-stand test and the choice of a tricycle with a high seat ( $r_s =$ 0.37, p = .024).

## Age

Participants from 8 to 13 years were represented in all three tricycle categories, comprising 38% of the sample (Figure 2). The results showed that all participants over 50 years (n = 5) applied for a low tricycle, but this tricycle category also contained participants with a wide age range (from 7 to 79 years).

## 6-min walk test

The 6-min walk test showed that 51.5% of the participants could end up in either of the three tricycle categories (Figure 3). Also, participants applied for a low tricycle regardless of their score on this test. In other words, participants who scored 200 m and 550 m applied for the same tricycle.

## Sex

Sex was correlated with tricycle choice, but only when the categories "medium" and "low" were merged, where more women applied for low tricycles. When three categories were kept, the







Figure 1. Images of the three tricycle categories. High seat = >70 cm, medium seat = 57-63 cm and low seat = <57 cm.

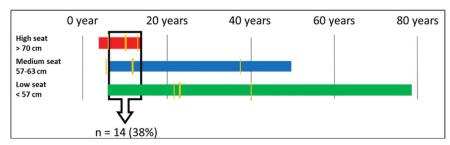


Figure 2. Type of tricycle related to age in years. The thick, vertical, yellow lines represent the medians and the thin yellow lines represent a 95% CI.

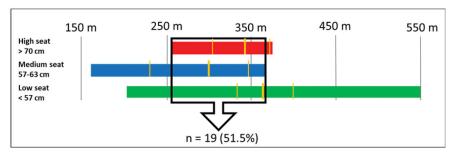


Figure 3. Type of tricycle related to scores on the 6-min walk test in metres (m). The thick, vertical, yellow lines represent the medians and the thin yellow lines indicate a 95% CI.

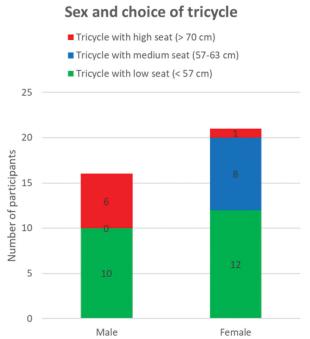


Figure 4. Choice of tricycle based on sex.

same trend did not appear. Specifically, men were represented in the "high" and "low" category but were absent in the "medium" category (Figure 4).

## 30-s sit-to-stand test

For the 30-s sit-to-stand test, the number of participants in the same "window" was 70% (Figure 5). Participants who scored in the wide range of 7–20 applied for a high tricycle. Still, there is a trend of participants with lower scores applying for a tricycle with a low seat and those with higher scores applying a high seat tricycle.

#### Trunk impairment scale

For the Trunk Impairment Scale, 75.5% of the participants scored within the same "window" (Figure 6). Participants with scores between 12 and 16 applied for a tricycle from any of the three categories.

## Oxford scale

Participants both with reduced and normal muscle strength applied for tricycles in all three categories (Figure 7). In the "medium" category, three times as many with reduced muscle strength applied compared to those with normal muscle strength. However, the total number of participants in this subgroup is small (n=8).

## Range of motion

Participants with a reduced range of motion in either of the tested joints applied for tricycles from all three categories. The total number of applicants with a reduced range of motion in their joints was low, which also means that the number in each tricycle category was low. Only one participant with reduced range of motion applied for a high tricycle, but many participants with a normal range of motion applied for tricycles in both the high and low tricycle categories, with fewer in the medium category (Figure 8).

## Power output

About two-thirds (60%) of the participants applied for the tricycle with a higher power output. For those subjects, the mean power output was 52.5% (SD=51.3, range = 2–155%) higher than the tricycle not selected. Forty per cent of the participants applied for the tricycle with a lower power output. For those subjects, the mean power output was 21.1% (SD=20.9, range = 2–80%) lower than the tricycle not selected.

## Participants' reasons for choice of tricycle

Seventeen participants (46%) answered the two open-ended questions regarding reasons for choice of tricycle. The feeling of

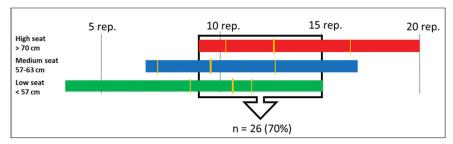


Figure 5. Type of tricycle related to scores (repetitions) on the 30-s sit-to-stand test. The thick, vertical, yellow lines represent the medians and the thin yellow lines indicate the 95% Cl.

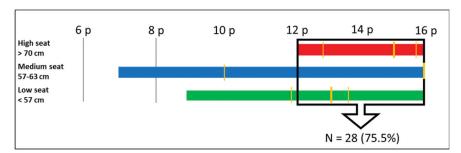


Figure 6. Type of tricycle related to scores on the Trunk Impairment Scale (0-16 points). The thick, vertical, yellow lines represent the medians and the thin yellow lines indicate a 95% CI.

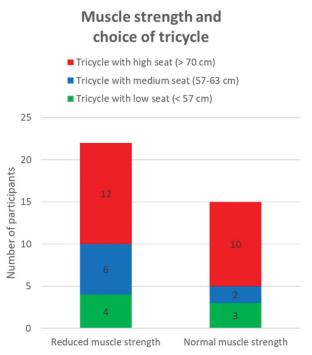


Figure 7. Type of tricycle related to muscle strength as measured with the Oxford Grading Scale for manual muscle testing. Reduced = 0–4 of 5, normal =5 of 5.

being safe, the ability to master cycling and comfortable sitting position were reported to be the main reasons for choosing the exact tricycle over the others (see Table 2). Other important characteristics of a tricycle were reported to be that stability, and an assistive motor with sufficient battery capacity to assist in steep uphills (see Table 2). Self-reported reasons for choice of tricycles are presented in Table 2.

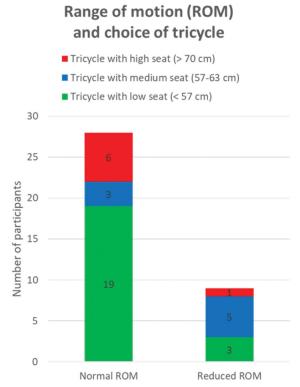


Figure 8. Type of tricycle related to the range of motion (ROM) in legs and arms as measured with a goniometer. Reduced ROM = reduced in at least one joint.

## **Discussion**

It is known that many people with disabilities struggle to reach the recommended amount of physical activity. For quite a few, cycling is a motivating and feasible way of being physically active

**Table 2.** Participants' reasons for choice of tricycle (n = 17).

What was decisive for choosing the exact tricycle that was applied for?			What characteristics of a tricycle are important to you?			
	n	%		n	%	
Safety	6	35	Stable	10	59	
Mastery	5	29	Sufficient battery capacity	9	53	
Comfortable sitting position	4	24	Comfortable sitting position	8	47	
Tailor-made and user friendly	3	18	Shock absorption	3	18	
Cool	3	18	User friendly	3	18	
Suitable for the place it is to be used	2	12	Rear wheel drive	1	6	
•			Off-road properties	1	6	
			Low weight	1	6	
			Luggage space	1	6	

[8,18,20]. Norway has a well-developed nationwide system that gives people good access to adaptive activity equipment. Still, some have limited access because funding is limited for those over 26 years of age and some might have difficulties managing the co-payment. Therefore, opportunities to participate in cycling might be different within a group of people with physical disabilities.

For those with the opportunity to access an adapted tricycle, it is important to find an appropriate one. However, knowledge of how to select an adapted tricycle varies among local therapists within Norway [17]. The selection of tricycles is large and ever increasing. The 37 participants in this study applied for a total of nine different tricycles, each of which is available with different opportunities for adjustments. Given that people applying for an adapted tricycle present with a wide variation in functional abilities, it is beneficial they have a wide choice in products. However, the complexity of finding a suitable tricycle for each unique individual is challenging, which sets requirements for the professional and the person with a disability to find the most suitable bike.

Some people with disabilities might need a tandem tricycle, especially those with visual impairment or severe physical impairment. However, we chose not to include people who applied for a tandem tricycle, because then the adaptation is not only focussed on the person with disability but also to the companion who contribute with some or all the propulsion.

The findings in this study suggest that age, gender and result on the 6-min walk test might be associated with the choice of a well-adapted tricycle. Still, none of the mentioned tests could alone predict the most appropriate type of tricycle for a specific person with a complex disability.

## Age

Age had the highest correlation to bike type. One-third of the participants were in an age category where all three bike types were represented (i.e., 8–13 years), meaning that younger cyclists could end up on either of the tricycles. It seems clear that adults did not apply for tricycles with high seats. All participants over the age of 50 applied for the recumbent bikes. Even though there are many different tricycles in the recumbent category, and multiple aspects need to be considered to conclude which tricycle is the most appropriate, results from this study suggest that people over 50 years reasonably can start by testing a type of recumbent tricycle.

## 6-min-walk test

The results from the 6-min walk test suggest that many people with disabilities, regardless of endurance capacity, might benefit from using a low tricycle. One of the reasons why this test was

included in the study was the assumption that it might separate those who needed an assistive motor from those who did not. However, only two participants applied for a tricycle without an assistive motor. This test could not separate between those who benefitted from an assistive motor and those who did not need one. The results from this study show that most people with disabilities benefit from a tricycle with an assistive motor. Many people with disabilities have lower endurance capacity than the general population [37] and might benefit from an assistive motor to be able to follow friends and family when cycling. For many people, this social aspect might be the most important reason to cycle. The assistive motor might be the factor that enables them to be involved in social cycling activities [22]. Also, a trend among Norwegians, in general, is to buy ordinary two-wheeled bikes with an assistive motor for transportation to work and leisure activities. Riding a tricycle with an assistive motor enables people with disabilities to follow this trend.

## Sex

Although no men applied for the medium tricycle, it is likely they would also find a medium tricycle appropriate because they fit on both higher and lower tricycles. This result may be different with a larger sample size.

## 30-s sit-to-stand test

This test demands both strength in lower extremities and balance [32], which are factors that might affect the choice of bike type. As seen in Figure 5, there was a slight trend, that those with higher scores on this test applied for a tricycle with a high seat. Despite this trend, the percentage of participants who scored in the same "window," and thereby applied for either of the three tricycle categories, was as much as 70%. A "cut off point," that separated the three categories was not observed, which means that completing this test did not seem to help people with disabilities or their therapists chose the most appropriate tricycle.

## Trunk impairment scale

The Trunk Impairment Scale was included in the study with the assumption that people with a lower sitting balance would benefit from a low and wide seat with a backrest. This assumption was confirmed to some extent, since all participants applying for the high tricycle scored high on the Trunk Impairment Scale. Yet, these test results could not predict tricycle choice, since many participants with high scores also applied for the two other tricycle categories. The result suggests that a low tricycle also is relevant for several people with good sitting balance. The reasons for this relevance might partly be explained by characteristics of the low tricycles that the high ones do not have, such as (1) the

possibility of shock absorption for less back pain and thereby better comfort, and (2) a lower centre of gravity that allows higher speed in turns with a higher level of safety.

#### Oxford scale

No pattern was observed concerning whether participants with low muscle power chose bike types with a specific angle between seat and pedals. Since muscles have different prerequisites for generating power in different positions [38], a hypothesis before conducting the study was that people with reduced muscle strength in their legs would prefer one specific bike type. The tricycles with backrests provide support to their back when pedalling, creating a counterforce, which might give an advantage when creating power; however, this hypothesis not confirmed.

#### Range of motion

To suggest that range of motion can predict tricycle choice, a trend of reduced range of motion should have been observed as people chose a tricycle with a higher or lower seat compared to the centre of the pedals. Such trend was not seen in this study. Therapists should not base the choice of higher or lower seat on reduced or not reduced range of motion. It seems that all three tricycles categories can fit for people with reduced range of motion in their lower extremities. However, two participants with reduced range of motion in their arms applied for a medium and a low tricycle, which have the handlebar closer to the seat than the high tricycle.

## Power output

The power output factor seemed to have a larger influence on tricycle choice as the difference between power output scores on the tested tricycles increased. It might be that when differences in power output measures were small, other factors were more relevant for tricycle choice. When the difference was larger, and the cyclists could feel a noticeable difference, they were more likely to choose the tricycle on which they managed to pedal with the most power output.

## Participants' reasons for choice of tricycle

Comfort was not surprisingly, reported to be important for choice of tricycle. In addition, the participants highlighted the importance of an assistive motor that could help them reach to the places they want. Norway is a country with varied terrain, steep hills and scattered settlements, which means that many, including people without disabilities, benefit from an assistive motor. The feeling of safety was also reported to be important. Safety seemed partly to be about having a stable tricycle with low risk of falling, but also about having a tricycle that was easy to manoeuvre and to have breaks that were easy to reach and use. The feeling of mastery was also highlighted as important for the choice of tricycle. This factor is reported to be crucial for sustaining physical activity [39,40], and should therefore be considered as one of the most relevant factors in order to ensure sustained cycling activity.

## Overall interpretation of the results

Evaluation of these results might suggest that relevant factors for choosing a well-adapted tricycle are even more complex than the factors tested in this study (i.e., strength, endurance, balance and range of motion). However, people over the age of 50 ended up applying for a recumbent tricycle and young people with good sitting balance tended to apply for a tricycle with a high seat. Many other aspects can be relevant, including other physical skills, local environment, pain, motivation, preferences and selfimage [18,19,39]. The answers on the questionnaire supported that safety, comfortable sitting position and the ability to master the tricycle had great importance. In addition, almost all participants benefitted from an assistive motor.

The intended use of the tricycle is crucial; for instance, a different type might be required if the tricycle is primarily meant for transport in the local community versus outdoor life in the forest. At Beitostølen Healthsports Centre, experience-based procedures for testing and adaptation of tricycles have been developed over the years. Professionals use strategies from the theoretical framework of adapted physical activity [27]; adapting the preferred activity to the athlete with the use of adaptive equipment when they plan to apply for a tricycle together with the cyclist. Years of experience with the adaptation of different bikes to different people in different environments is key to success. Cooperation with the cyclist, and colleagues when necessary, in addition to multiple testing over several days, results in a well-adapted tricycle. The factors that are relevant for each person vary and seem to require an individually tailored adaptation process. We found no clear pattern of which factors are most significant for which person in this study, indicating individual combinations of factors are crucial. This might indicate that consulting with an experienced professional who can determine the most relevant factors for each person is valuable for selecting the most appropriate tricycle. However, more research is needed to determine the most crucial factors for choosing and adapting appropriate adaptive tricycles to increase therapists' knowledge and ability to help clients effectively.

## Strengths and limitations

Although the sample of this study was sufficient for an observational study, the large number of bike categories limited our ability to identify potential associations. However, a larger sample may not produce clear trends given the wide range of tricycles and people. There might be, and most likely are, relevant factors for choosing the best tricycle that are not included in this study. Still, the study includes a large variety of factors and a diversity of disabilities, which strengthen the transferability of the results to other contexts. Further, the study has been conducted in a country with a well-developed system for procuring adapted tricycles, which prevents socio-economic bias of the participants.

## Conclusions

None of the conducted standardized tests could predict the right adaptive tricycle for each person alone. Participants over the age of 50 applied for one of the five recumbent tricycles, and only young participants with good sitting balance ended up with a tricycle with a high seat. Most participants benefitted from, and, therefore, chose, a tricycle with an assistive motor. Safety, comfort and mastery were stated as important factors when choosing the most appropriate tricycle. Large variations among people with

disabilities, bike types and possible adjustments indicate individual-level analyses are necessary to find the most appropriate tricycle.

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# ARTICLE

Acquiring a tailor-made tricycle: Implications for people with disabilities







Exploring physical activity level after procurement of adapted tricycle;

Quantity versus enjoyment





Article

# Exploring physical activity level after procurement of adapted tricycle; Quantity versus enjoyment

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**Abstract:** People with disabilities are less active than people without disabilities, and many do not reach the recommended amount of moderate intensity physical activity. This study aimed to investigate whether people with disabilities who acquired an individually adapted tricycle became more physically active, and to map which factors they reported as important for using their tricycle. People with disabilities applying for an adapted leg-driven tricycle participated in this observational study. ActiGraph GT3x accelerometer was worn for 7 days before and after acquiring the adapted tricycle (pre- and post-test). An open-ended question, in a questionnaire described factors important for tricycle use. Forty-five participants were included, aged 5 to 79 years (Mean = 32.3 years, SD = 22.7) with a large variety of complex disabilities, most with mobility impairments and some with intellectual disability. No significant change in activity level from pre- to posttest was found. However, individual differences were large. Reported reasons for not using the tricycle were bad weather conditions, pain when or after cycling, and insecurity. Reasons for using the tricycle were reported to be increased mobility, joy, and the feeling of freedom. To identify modifiable facilitators and barriers for using an individually adapted tricycle is crucial for regular use.

**Keywords:** adapted physical activity; disability; accelerometer; self-report motivation; facilitators; barriers

## Introduction

There are numerous benefits to a physically active lifestyle, and many chronic medical conditions can be prevented with regular physical activity (Rhodes et al., 2017). However, only three out of ten adults in Norway meet the recommended amount of moderate intensity physical activity (Hansen et al., 2014). Approximately 90% of 6-year-olds meet the recommendations, whereas less than 50% of 15-year-olds do so (Steene-Johannesen et al., 2019). In addition, people with disabilities are less active than people without disabilities (Martin Ginis et al. 2021; Züll et al., 2019). Researchers have found that intrinsic motivation and self-efficacy are factors that correlate strongest with physical activity for people with and without disabilities (Rhodes et al., 2017; Saebu & Sørensen, 2011). To meet physical activity recommendations over time, it is important for people to find an activity they master and enjoy (Imms et al., 2017; O'Donovan et al., 2010).

Cycling is a widespread activity, but people with disabilities might find cycling with mass-distributed equipment difficult. They can therefore benefit greatly from individually adapted bikes (Bedell et al., 2013; Gjessing et al., 2018). The possibilities for adaptations are many, for instance, different pedals offer support for the feet, and there are seat types and

support for the upper body. Tricycles are the most commonly adapted equipment for physical activity in Norway (Oslo Economics, 2020). All people with a disability, with a permanent need for an adapted tricycle, can apply. To acquire these tricycles, people contact a physical or occupational therapist, who can then apply to the Norwegian Labour and Welfare Administration (Rikstrygdeverket, 1997). Testing and applying can be done during a stay at a regional or national rehabilitation centre in the specialist health care system, or in the municipality where the individual lives. The procurement of an individually well-adapted tricycle might enable more people with disabilities to increase or maintain their physical activity level. Many children with disabilities cycle, but even more want to do so (Nyquist et al., 2016).

Research conducted in the field of adapted equipment for physical activity describes benefits of use, but also challenges in the system of application and training, and the researchers encourage further research (Bergem, 2020; Pedersen et al., 2019; Pedersen et al., 2019b; Pickering et al., 2013). One article about the adaptation of tricycles (Gjessing & Jahnsen, 2021) and one study exploring the implications of acquiring a tailor-made tricycle (Gjessing et al., 2022) has been published.

Since the possibilities for people with disabilities to procure adapted tricycles are relatively large in Norway, many should have the opportunity for a pleasurable way of being physically active in their local environment. This could lead to numerous health benefits. However, to the authors' knowledge, no studies have been conducted to evaluate whether procurement of such a tricycle leads to more physical activity. Therefore, this study aimed to explore whether people who acquired an individually adapted tricycle became more physically active in their daily life. It also aimed to map the factors people reported as important for using or not using their tricycle.

## **Materials and Methods**

## Design

The present study applies an observational design. Ethical approval for this study was applied for. The Regional Committee for Medical and Health Research Ethics in Norway considered the study to fall outside the Health Research Act (ref.:2018/1349) and concluded that ethical approval was not necessary. The Norwegian Centre for Research Data approved this study (ref.: 549301), and the identity of the participants is anonymised.

## Participants, context and inclusion procedures

Participants with disabilities who applied for an adapted three-wheeled, leg-driven tricycle (not tandem) were recruited from professionals working at three Norwegian Labour and Welfare Administration offices (in the south-east, mid and north of Norway), in five municipalities (in the south-east of Norway) and at Beitostølen and Valnesfjord Healthsports Centres. The Healthsports Centres are parts of Norwegian specialist healthcare system, and offer persons with disabilities secondary rehabilitation for one to four weeks (Røe el al., 2008), based on the theoretical framework, based on the Adapted Physical Education Model (Sherrill, 2004). Participants who were not at a Healthsports Centre, lived their ordinary life in their local community, and contacted a local therapist to start the application process. Inclusion criteria included, at least five years old, and understanding Norwegian or English language. Inclusion was not limited to any specific diagnosis, since the possibility to procure a tricycle is not limited to specific diagnoses, but to function and need. Written informed consent was collected from participants 16 years of age and older, whereas parents signed for participants below 16 years. The participants themselves or their medical records were the sources of diagnosis and sociodemographic data.

## **Data collection**

Data were collected from May 2019 to November 2020. A pre-test, wearing an accelerometer for seven days, was performed after the participants had tested tricycles in order to apply for one, but before they received their tricycle. The participants who tested tricycles as part of their rehabilitation programme at a Healthsports Centre performed the pre-test after they returned home. For the post-test, participants wore an accelerometer for another seven days, after the participants had the opportunity to use their acquired tricycle for at least three weeks. Accelerometers were delivered to the participants at the time of tricycle testing or sent by surface mail. They all received a franked envelope to return the accelerometer after the period of measurement was completed. In cases where participants received their tricycle during winter, they waited to complete the post-test until spring, when the roads were no longer covered with snow.

## **Outcome measures**

## Accelerometer

ActiGraph (Pensacola, FL, USA) is a widely used accelerometer (Romanzini et al., 2014). The ActiGraph model GT3X weighs 27 grams and has small dimensions (3.8 cm x 3.7 cm x 1.8 cm). It has a triaxial accelerometer that collects information in three axes (vertical, medio-lateral and antero-posterior) and can combine this information into a vector magnitude. Participants with walking ability wore the accelerometer on their right hip, fastened with an elastic band. Participants using wheelchairs wore the accelerometer on their non-dominant wrist. Participants were instructed to wear the accelerometer from when they got up in the morning until they went to bed at night. They removed the accelerometer when showering, when swimming, or performing other activity in water. Activity performed without the accelerometer was reported on a form and included in the analyses as light activity. The form also contained a question regarding whether the participants' activity level had been about normal during the week of measurement.

## Questionnaire

At the same time as the participants received the accelerometer, they also received a questionnaire with questions regarding their cycling. The questionnaire was created on Typeform, and a link was sent to the participants or their parents via e-mail. Most of these results have been presented and discussed in an earlier article (Gjessing et al., 2022). The questionnaire also contained an open-ended question about their own cycling, which is relevant for the aim of this study: "Do you have other comments regarding your cycling?" Participants commented on issues perceived as relevant for their cycling. They gave several reasons for using or not using their tricycles, and these comments are reported in this article. The open-ended question is the only part of the questionnaire used in this study.

## Analyses

Descriptive analyses were conducted to reveal sample characteristics. Time in different activity levels – low, moderate and vigorous – was given in minutes. Cut-off-points for each activity level were: sedentary: 0–99 counts/min, light: 100–1999 counts/min, moderate: 2000–4999 counts/min, and vigorous: 5000 counts/min and above (Aadland & Ylvisåker, 2015; Stålesen et al., 2016). In addition, the accelerometer counted steps. Skewness was found in parts of the data regarding moderate and vigorous intensity activity. Logarithmic transformation converted to normally distributed data, and allowed the use of a paired t-test. Cohen's d was used to find the effect size, with the following interpretation: 0.0<0.2 = negligible, 0.2<0.5 = small, 0.5<0.8 = medium and 0.8 or more = large (Laake et al., 2015). A Spearman nonparametric correlation test was performed to determine the amount and

significance of correlation between the different factors. A correlation of 0.5 or higher was considered moderate, whereas 0.8 or higher was considered high (Akoglu, 2018). The level of significance was set to a *p*-value of .05 or lower. Mainly, SPSS version 25 was used to record and analyse the accelerometer findings. SPSS version 27 was used to make an additional calculation of effect size that could not that could not be completed in older versions.

Responses to the open-ended question in the questionnaire were translated and categorised in groups according to the characteristics of the comments. Statements from the participants were preserved as they were written, to prevent changing of the meaning content. The grouping of comments was based the authors' assessments of whether they belonged in the category of positive or negative comments, or on whether the participant had a positive or negative change in physical activity level from pre- to post-test. Relevant points from the standards for reporting qualitative research (SRQR) (O'Brien et al., 2014) were used.

## Results

In total, 66 people consented to participate. Some were excluded from the study because they ultimately got a tandem bike (n=2), or because they could not be reached (n=5). Thereby, agreement regarding measurement with the accelerometer was not made. A few accelerometers were returned without being used (n=3). Another 11 participants did not get the opportunity to wear the accelerometer the second time because they did not receive their tricycles before the cycling season ended. Some of these participants waited more than one year. Both a pre- and post-test with accelerometer-testing for seven days were conducted by 45 participants. Their results constitute the basis for the analyses. Dropout analysis showed that the group of 21 not included were similar to the group of included participants (Table 1).

**Table 1.** Sample characteristics of included and excluded participants' age, sex, place of residence, diagnosis, and location for the application procedure. Chi-square test to detect possible differences between the groups.

Included Excluded Chi-square test (n=45)(n=21)% % Value Age\* 30.199 .778 5 - 1020 28.5 11 - 1622 10 21-29 16 14 43-50 19 18 53-79 24 28.5 Sex .340 .560 Female 60 52 Male 40 48 .792 Place of residence .07049 City 52 Rural 48 51 Diagnosis .696 .874 Neuromuscular diseases 42 33 Cerebral Palsy 20 24 Intellectual disability 13 19 25 24 Others 1.677 .195 Applications conducted Health sports centres 64 48 Local therapists 36

<sup>\*</sup>No participants were between 17-20, 30-42, and 51-52 years old.

The participants ranged from 5 to 79 years old (Mean = 32.3 years, SD = 22.7). They happened to be spread into two age groups: under 30 and over 42 years of age. There were more female than male participants, but the distribution of rural or urban place of residence was equal. There were participants from all the Norwegian counties. The participants presented a large variety of complex disabilities, such as cerebral palsy, which was the most common diagnosis (20%). Examples of other diagnoses were multiple sclerosis, muscular dystrophy, osteosarcoma, myopathy, spina bifida, stroke, spinal cord injury, other rare congenital syndromes, delayed psychomotor development and Down syndrome.

## **Testing**

Most participants used the accelerometer within the time frame of three to five weeks after they got their tricycle. However, nine participants got their cycle too late in the autumn or during winter to conduct post-test within this time frame. These participants were tested three to five weeks after they had opportunity to start their cycling season the following spring.

## Accelerometer results

**Step counts (steps)** 

The results from the paired samples t-test showed no statistically significant change in activity level from pre- to post-test, neither in terms of light, moderate or vigorous intensity physical activity, nor step counts (Table 2). The effect size between the two time points were negligible.

	Pre-test		Post-te	Post-test			
	Mean	SD	Mean	SD	Change	p	d
Light activity (min)	1499	510	1476	510	- 23	.67	0.063
<b>Moderate activity (min)</b>	715	479	655	371	- 60	.50	0.165
Vigorous activity (min)	115	124	106	115	- 9	.65	0.096

38321

- 1820

.47

0.109

20801

Table 2. Paired samples t-test showing mean activity level at pre- and post-test, and effect size.

The Spearman nonparametric correlation test there were conducted to seek for correlations between activity level and sex, age, diagnosis or place of living. However, the test showed no statistically significant correlations (Table 3).

<b>Table 3.</b> Spearman $(\rho)$ nonparametric correlation tests between activity level and sex, age,
diagnosis and place of living.

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	Diff I	MVPA	Diff Steps		Se	Sex		ge	Diagnosis	
	ρ	p	ρ	p	ρ	p	ρ	p	ρ	p
Diff Steps	.769	<.001	-							
Sex	042	.785	.140	.360	-					
Age	.248	.101	.200	.187	108	.478	-			
Diagnosis	020	.896	089	.562	.081	.597	102	.505	-	
Place of living	.038	.806	<.001	1.000	109	.476	164	.280	.115	.450

Note: Diff MVPA = Difference in Moderate-to-vigorous physical activity, Diff Steps = Difference in step count

Regarding the change in moderate- to-vigorous activity intensity (MVPA) from pre-test to post-test, the variation was large. The spread from one participant with an increase in MVPA of 104% to another with a reduction of 74% (Figure 1). Two-thirds of the participants had an increase or a reduction in MVPA of 40% or less. When it comes to step counts, two positive results with an increase of 227% and 202% stand out, while the rest were spread from an increase of 92% to a decrease of 79%. Three-quarters (73%) of the participants had an increase or a reduction of step counts of 40% or less. Some participants had quite different results across the MVPA count and step counts. Some had a negative or positive

change in both parameters, whereas some had a negative change in one parameter and a positive change in the other. Despite these differences in MVPA-scores and steps-scores, the two parameters were closely correlated (.77) (p = < .001).

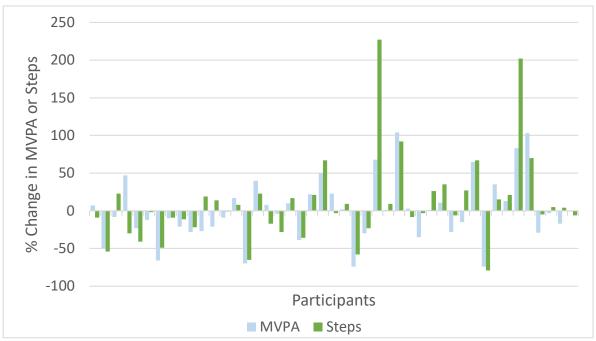


Figure 1. Change in MVPA and steps (%) from pre- to post-test.

## Questionnaire results

Thirty-two participants used the opportunity to answer the free-text question in the second questionnaire (See Table 4). Of these, 10 reported reasons for why they did not use the tricycle as much as they planned. The main reasons reported were small amounts of cycling were due to the weather conditions (n = 4) and feeling insecure on the tricycle or in traffic (n = 3). Other reasons mentioned were pain when or after cycling (n = 2) and low amounts of cycling because the participant did not remember that it was a possible activity (n = 1).

Twenty-two participants described positive experiences with their received tricycle. The answers mainly included the three themes, increased mobility, freedom, and joy. The theme, increased mobility, concerned the use of the tricycle as a means of transport in the local community. Also, it reflected movement over larger distances than what was possible prior to receiving their tricycle. The theme, freedom, consisted of the feeling of being independent and the possibility to travel to places they wanted to go without having to plan it with others. Examples of statements from the participants were, "I can leave and come back whenever I want. It's like getting my life back!" and "I feel free!" The third theme, joy, contained expressions from the participants about the fact that using the tricycle gave them a lot of pleasure. They expressed their relief that they could finally reach high speeds and feel the wind in their hair. "I love cycling at high speed!" and, "the bike is fantastic and gives me lots of fun!" were statements from two participants.

When these comments are matched to the results from the device measure of physical activity level, it is clear that there are some comments that can explain the decrease in activity level from pre- to post-test (Figure 2). The figure also shows that one participant reported cycling a lot, but still had a decrease in general physical activity level.

 Table 4. Participant comments.

	Positive comments	Negative comments
Comments from participants with a positive change in MVPA- and step-counts	Cycling has given me a new life. I am not dependent on anyone. I can leave and come back whenever I want. It's like getting my life back. The bike is fantastic and gives me lots of fun! Female, 60 years old.  I love cycling at high speeds! Female, 10 years old.  It is amazing to have the opportunity to cycle again! Female, 58 years old.  I feel more mobile with the bike, and I can be outside, which I love! Female, 50 years old.  Cycling gives me freedom, self-esteem and joy! Male, 59 years old.  Important with well-adapted bike paths. Male, 45 years old.  I cycle both in my local community and on longer trips. Male, 21 years old.	The bike works fine, but I'm in strong pain after longer rides.  That, plus the generally worse shape, makes it harder to find motivation for cycling. Female, 65 years old.  Little cycling due to illness and a lot of rain. Female, 10 years old.  I have not cycled that much lately because of rainy weather. Female, 22 years old.  Important with well-adapted bike paths. Male, 45 years old.  Little cycling due to a bit too much spasticity and snow/ice in the hill down from my house. Male, 59 years old.
Comments from participants with a positive change in MVPA-count and negative change in step counts or vice versa	I feel free! Male, 12 years old.  I am very happy with the type of bike I have now. Female, 53 years old.  Great to get out! Female, 50 years old.  I'm in better shape now. I'm glad there is not much «secondary» pain after cycling. Male, 54 years old.  I like cycling on asphalt or in the woods. I prefer bikes with good shock absorption. Female, 21 years old.  I think it's nice to cycle over long distances. Male, 9 years old.	I struggle to remember that cycling is a possible activity. Female, 21 years old.
Comments from participants with negative change in MVPA- and step-counts	Cycling is very weather-dependent. Male, 68 years old.  My tricycle is beneficial as a means of transport. Female, 24 years old.  I love my tricycle! I have been cycling a lot the last two months. Male, 27 years old.	Cycling is very weather-dependent. Male, 68 years old. We will focus on more cycling when the weather improves! Male, 13 years old. I have cycled little because of back problems. Male, 63 years old. Too bad, the new bike was not adapted when I received it, so I did not get to use it this season. No cycling due to snow and ice. Female, 8 years old. It's a bit difficult to keep pedalling when the speed gets too high. Female, 9 years old. He seems to feel a bit insecure on his new tricycle. I feel he is struggling a bit with the balance. Mum of 12 years old boy.



**Figure 2.** Change in MVPA and steps (%) from pre- to post-test, including participant comments.

#### Discussion

Results from the accelerometers worn by fourty-five participants before and after the procurement of an individually adapted tricycle showed no statistically significant changes in physical activity levels. Variations in physical activity levels among the participants were large, both regarding positive and negative changes. These variations did not correlate significantly with diagnosis, age, sex or place of living. Results from the open-ended question regarding their own cycling showed that main reasons for low amounts of cycling activity were weather conditions and feeling insecure on the tricycle or being in traffic. The main positive experiences described were increased mobility, freedom, and joy.

#### Not more active, but satisfied

At the group level, there was no statistically significant change in physical activity levels after the participants received an individually adapted tricycle. Some of the five cases – related to limited use due to pain or insecurity when using the tricycle – might be related to the tricycle itself, and such experiences could be reduced with further adjustment of the tricycle or a change to another model (Gjessing & Jahnsen, 2021). A change of seating position could provide pain reduction, and another tricycle with a lower centre of gravity or more support to the upper body might reduce the uncertainty related to sitting balance.

Almost two-thirds (64%) of the participants applied for a tricycle during a rehabilitation stay. Researchers have found increased physical functioning for adults one year after such a rehabilitation stay (Preede et al., 2015; Skatteboe et al., 2016). However, the amount of physical activity did not improve correspondingly (Skatteboe et al., 2016). Regarding children, physical activity level is expected to decrease during adolescence (Dumith et al., 2011; Majnemer et al., 2008). Nevertheless, children and youths participating in a rehabilitation stay had a stable physical activity level over a 15-month period, even if participation in other leisure activities were reduced (Baksjøberget et al., 2017). The claim that a steady activity level might be considered positive, is supported by Hammel and colleagues (2008), who claimed that "more is not necessarily better" (p1445-1460) and

highlighted the importance of enjoyment as the key indicator of successful participation. As seen in the results of this study, many participants, both children and adults, expressed satisfaction and joy when they used their newly procured tricycles. The results in a previously published article with data from the same study (Gjessing et al., 2022), showed that the participants used their tricycle regularly (median of once a week). They were also satisfied with their own cycling, with a median score of 4 on a 5-point scale. Even though the participants in the present study on average were not more active, it might be that they were active in a manner they preferred. Performing an activity you enjoy has been found to be a key indicator of successful participation (Imms, 2008). Preede and colleagues (2015) found that people with disabilities can express a high level of satisfaction without an increased amount of physical activity. It might be that they do not find the time or energy for more physical activity in their everyday life, but have found activities that they are more satisfied to perform.

### Large variations

The participants showed large variations regarding change of MVPA from pre- to posttest. One participant with a reduction of 74% and another with an increase of 104%. The results from the accelerometer and the statements from the participants showed that some participants had a large increase in physical activity level and had many positive experiences with their new tricycles. It can therefore be concluded that an adapted tricycle can give individuals positive experiences in activity and contribute to an enjoyable active lifestyle.

The large reduction in physical activity levels of some of the participants can be explained by concrete reasons, such as increased pain or illness (Hodges & Smeets, 2015; Li & Chen, 2012). Other participants did not have similar reasons for a reduced activity level. They might have been less active for a short period due to bad weather or other variable factors, or they might have been in a longer period of life with a lower activity level. Some participants with quite a large reduction in physical activity levels stated that they had been physically active and had cycled many miles during the last few months. The difference in self-report physical activity and device-based measures of activity supports the need for both (Colley et al., 2018). Nonetheless, one previous study has shown that the ActiGraph GT3X under-report the amount of cycling activity (Hansen et al., 2014). The ActiGraph GT3X was chosen because it was found to be the most appropriate to measure general activity level.

The large variations among the participants suggests a need for close follow-up after each person receives an adapted tricycle. This could reveal the potential reasons for the small limited use, and assess whether these are reasons that can be addressed. Li & Chen (2012) found that professional support was an important factor for staying physically active. The professional's knowledge about equipment and motivation for physical activity might contribute to higher activity level among people with disabilities.

The participants in this study had a large variety of different disabilities and physical functioning, but some diagnoses were not as related to an increase or decrease in general activity level as others. Saebu & Sørensen (2011) found that factors related to functioning and disability did not explain variations in physical activity. Factors related to motivation and self-efficacy, however, explained more of the variation. Intrinsic motivation is a factor strongly associated with physical activity (Saebu & Sørensen, 2011; Steinhardt et al., 2020). Several statements from the participants in this study express their satisfaction and joy when using their tricycles. Ryan and Deci (2000) strongly connected joy in activity to intrinsic motivation, and thereby increased chance of continued activity. Scarpa (2011) claimed that adolescents and young adults practicing in sport had positive self-concept and high self-esteem, which again facilitates more physical activity. A focus on such positive experiences

in activity is therefore recommended when professionals meet with people with disabilities (Rosenbaum & Gorter, 2012).

### Strengths and limitations

The most obvious limitation of this study is the time frame, in two different manners. First, because of the delay from applying for a tricycle to receiving one, many other factors than the tricycle itself might affect the participants' physical activity level. The season of the year is different, general health condition might have changed and motivation for cycling, or other physical activity, might be different from the time of application. Second, the post-test was performed quite close after receiving the adapted tricycle. Since it can take time to learn new skills and incorporate new habits, it would be valuable to implement another follow-up measure using accelerometers after a longer period of time.

The intervention, with adaptation, trial and learning to use tricycles, was not standardised, since individual adjustments were essential and since each individual's surrounding factors would be difficult to control. Therefore, post-test results were only compared to each individual's pre-test.

The lack of consistency regarding the placement of the accelerometer might be considered a limitation. However, the authors considered that it was best to place it on the location reported as giving the most accurate measures (the hip). As some of the participants would naturally have produced misleading results with this placement, an alternative (wrist) was chosen for them. All participants wore the accelerometer at the same place at both periods of measurement. The placement of the accelerometer did not have a decisive meaning for the result, as the amount of activity was not compared across participants, but rather with measures from the same person at pre- and post-test. The accelerometer has previously showed to under-report cycling activity. Participants might therefore have cycled more than the accelerometer presented as moderate or vigorous activity.

The data collection was partly carried out during the COVID-19 pandemic. Some professionals might have been unable to perform their normal tasks for a period of time, which might have led to a somewhat deficient follow-up regarding the adaptation of tricycles upon delivery. Thereby, the results might have been slightly affected.

### **Conclusions**

Even though people with disabilities in Norway use their opportunity to procure an individually adapted tricycle, this does not necessarily lead to an immediate increase in general physical activity level in these people's lives. It seems important to pay attention to people's reasons for not cycling, so that reasons are acknowledged and changed accordingly. The weather conditions cannot be influenced, but the feeling of insecurity can be reduced with a longer trial and learning period to create a sense of mastery and security (Gjessing et al., 2022). Positive factors associated with cycling, such as the feeling of joy and freedom, indicate that participants were not more active, but more satisfied with their way of being active, which is also beneficial for their health.

### **Perspectives**

Since regular physical activity contributes to the prevention of many chronic medical conditions, and since cycling is seen as a gentle, relevant and enjoyable activity for many, it is very positive that so many people with disabilities in Norway have the opportunity to procure an individually adapted tricycle. At a group level, the participants did not increase their level of physical activity. Research exploring long-term effect on physical activity levels after procuring an adapted tricycle will therefore be relevant. Also, more research to identify modifiable facilitators and barriers to regular use of an acquired tricycle, both individual and environmental factors, is needed. Such facilitators and barriers might be addressed by

professionals, family and friends, and create better conditions for increased physical activity. Thus, more children, youth and adults with disabilities might meet the recommended amount of amount of physical activity, and enjoy the health benefits that an active lifestyle can bring.

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APPENDIX

Answer from the Regional Committee for Medical Research Ethics



Region:Saksbehandler:Telefon:REK sør-østHege Cathrine Finholt,22857547

Vår dato: 19.09.2018 Vår referanse: 2018/1349 REK sør-øst D

Deres referanse:

Deres dato:

12.06.2018

Vår referanse må oppgis ved alle henvendelser

Berit Gjessing Stiftelsen Beitostølen Helsesportsenter

### 2018/1349 Hva er best for meg?

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst D) i møtet 22.08.2018. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Forskningsansvarlig: Stiftelsen Beitostølen Helsesportsenter

Prosjektleder: Berit Gjessing

#### Prosjektleders prosjektbeskrivelse

Forskningen skal gi økt kunnskap om hvordan en treffsikker utprøving/tilpasning av sykkel som aktivitetshjelpemiddel best kan utføres. Dette kan øke aktivitetsgleden og bedre forutsetningene for deltagelse i eget lokalmiljø. Forskningsspørsmål: Kan sensorteknologi bidra til en mer treffsikker utprøving og tilpasning av sykkel som aktivitetshjelpemiddel? Kan en mer treffsikker utprøving og tilpasning av sykkel føre til økt mestringsopplevelse, aktivitet og/eller sosial deltagelse? Hvilke faktorer er fremmende og hemmende for økt sykkelaktivitet og deltagelse i brukerens lokalmiljø? Prosjektet er designet som en forløpsstudie med bruk av multimetode. Bruker skal svare på spørsmål om ferdighet og bruk av sykkel ved utprøving og etter 3 måneders bruk (CAPE og COPM). Sensorteknologi skal måle balanse på sykkel og kraft i tråkk/skyv ved utprøving av ulike sykler. Intervju med utvalgte brukere skal avdekke andre faktorer enn utprøving/tilpasning som er avgjørende for bruk av sykkel.

#### **Vurdering**

Formålet med prosjektet er å undersøke hva som er en treffsikker utprøving, tilpasning og opplæring i bruk av sykkel som aktivitetshjelpemiddel. Målet er at flere brukere får en sykkel som er bedre tilpasset sitt funksjons- og ferdighetsnivå. Komiteen vurderer at prosjektet, slik det er presentert i søknad og protokoll, ikke vil gi ny kunnskap om helse og sykdom. Prosjektet faller derfor utenfor REKs mandat etter helseforskningsloven, som forutsetter at formålet med prosjektet er å skaffe til veie "ny kunnskap om helse og sykdom", se lovens § 2 og § 4 bokstav a).

Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet. Det er institusjonens ansvar å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern samt innhenting av stedlige godkjenninger.

#### Vedtak

Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2 og § 4 bokstav a). Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet.

Komiteens avgjørelse var enstemmig.

# Klageadgang

REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn med korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff Professor em. dr. med. Leder

> Hege Cathrine Finholt, PhD Rådgiver

Kopi til:reijah@ous-hf.no

Stiftelsen Beitostølen Helsportsenter: post@bhss.no

APPENDIX 2 Approval letter from the Norwegian Social Science Data Services

#### **NSD Personvern**

06.12.2018 11:56

Det innsendte meldeskjemaet med referansekode 549301 er nå vurdert av NSD.

Følgende vurdering er gitt:

REK har vurdert at prosjektet faller utenfor helseforskningslovens virkeområde (2018/1349, REK sør-øst D)

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 06.12.2018 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

#### MELD ENDRINGER

Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

#### TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle særlige kategorier av personopplysninger om helseforhold og alminnelige personopplysninger frem til 27.08.2021.

#### LOVLIG GRUNNLAG

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Foreldre/foresatte skal samtykke for barn under 16 år. Ungdommer 16-17 år skal selv samtykke til deltagelse. Ut fra en helhetsvurdering av opplysningenes art og omfang, vurderer vi det slik at ungdommer 16-17 år har forutsetninger for å forstå hva deltagelse innebærer og kan samtykke til deltakelse på selvstendig grunnlag.

Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 a), jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

#### PERSONVERNPRINSIPPER

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen:

- om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

#### DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

#### FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må prosjektansvarlig følge interne retningslinjer/rådføre seg med behandlingsansvarlig institusjon.

#### OPPFØLGING AV PROSJEKTET

NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

APPENDIX Informed consent





# Forespørsel om deltakelse i prosjekt

# "Utprøving og bruk av sykkel"

### Hvorfor blir du spurt om å være med?

Dette er et spørsmål til deg om du vil delta i en undersøkelse når du skal prøve sykkel. Vi er nysgjerrig på hvordan du sitter på sykkelen og hvor hardt du tråkker/skyver. Hvis du får en sykkel hjemme, vil vi også spørre deg om hvor og når du bruker den der. Barn, ungdom og voksne som skal prøve ut og søke om sykkel er aktuell for å være med i prosjektet.

## Hva vil skje hvis du blir med?

Vi vil at du skal svare på noen spørsmål på et ark før du prøver sykkel. Så vil vi sette en liten brikke øverst på ryggen din, som måler hvordan du sitter på sykkelen når du prøver den. Vi vil også måle hvor hardt du tråkker/skyver mot pedalene. Hvis du får en sykkel til å bruke hjemme, vil vi at du skal svare på det samme spørsmålsarket som du har svart på en gang før. Dette skal du svare på en stund etter at du har fått sykkelen. Det kan også hende at jeg vil snakke med deg for å stille deg noen ekstra spørsmål om hvorfor du bruker sykkelen eller hvorfor du eventuelt ikke bruker den. Dette kan du synes er litt uvant. Hvis du vil være med på det, kommer jeg til å ta opp samtalen. Mamma eller pappa kan være med hvis du ønsker det. Hvis du vil delta, må mamma eller pappa også synes at det er greit.

Hvis du vil være med i studien, skal du og din mamma eller pappa skrive navnet deres på et ark (samtykkeerklæring). Hvis du senere ønsker å trekke deg eller har spørsmål om studien, kan du kontakte Berit Gjessing på mail berit.gjessing@bhss.no eller telefon 95974111.













# Hva vil skje hvis du ikke blir med?

Du velger helt selv om du vil delta eller ikke. Du kan prøve sykler og eventuelt søke om å få en sykkel hjemme uansett om du er med i prosjektet eller ikke.

Med vennlig hilsen

**Berit Gjessing** Prosjektleder **Reidun Birgitta Jahnsen** Prosjektansvarlig





# Forespørsel om deltakelse i forskningsprosjektet

# Hva er best for meg?

Utprøving, tilpasning og opplæring av sykkel som aktivitetshjelpemiddel

## Hvorfor blir du spurt om å være med?

Dette er et spørsmål til deg om du vil delta i en undersøkelse når du skal utføre utprøving og tilpasning av sykkel. Vi er nysgjerrig på hvordan du sitter på sykkelen og hvor hardt du tråkker/skyver. Dersom du får en sykkel hjemme, vil vi også spørre deg om hvor og når du bruker den der. Barn, ungdom og voksne som skal prøve ut og søke om sykkel er aktuell for å være med i prosjektet.

### Hva vil skje hvis du blir med?

Vi vil at du skal svare på noen spørsmål i et skjema før du prøver sykkel. Så vil vi sette en liten brikke øverst på ryggen din, som vil måle hvordan du sitter på sykkelen når du prøver den. Vi vil også måle hvor hardt du tråkker/skyver mot pedalene. Hvis du får en sykkel til å bruke hjemme, vil vi at du skal svare på det samme skjemaet som du har svart på en gang før. Dette skal du svare på en stund etter at du har fått sykkelen. Det kan også hende at jeg vil snakke med deg for å stille deg noen ekstra spørsmål om hvorfor du bruker sykkelen eller hvorfor du eventuelt ikke bruker den. Dette kan du synes er litt uvant. Hvis du vil være med på det, kommer jeg til å ta opp samtalen.

Hvis du vil delta, må mamma eller pappa også synes at det er greit. Hvis du vil være med i studien, skal du og din mamma eller pappa skrive navnet deres på et ark (samtykkeerklæring). Hvis du senere ønsker å trekke deg eller har spørsmål om studien, kan du kontakte Berit Gjessing på mail <a href="mailto:berit.gjessing@bhss.no">berit.gjessing@bhss.no</a> eller telefon 95974111.













# Hva vil skje hvis du ikke blir med?

Du velger helt selv om du vil delta eller ikke. Du kan prøve sykler og eventuelt søke om å få en sykkel hjemme uansett om du er med i prosjektet eller ikke.

# Hva skjer med informasjonen om deg?

I prosjektet vil vi innhente og registrere opplysninger om navn, kjønn, alder, bosted og diagnose. Alle opplysninger om deg og alt du svarer på skjema eller i et eventuelt intervju, vil bli behandlet uten navn eller andre opplysninger som kan gjøre at du blir gjenkjent. Informasjon vil bli lagret på et sikkert sted. Det er bare prosjektleder som har adgang til en navneliste og som kan finne tilbake til deg. Opplysninger fra studien vil presenteres samlet (det er ikke bare dine svar som kommer frem). Alle opplysninger som du har gitt vil slettes etter at studien er ferdig.

Med vennlig hilsen

**Berit Gjessing** Prosjektleder **Reidun Birgitta Jahnsen** Prosjektansvarlig





# Forespørsel om deltakelse i forskningsprosjektet

# Hva er best for meg?

Utprøving, tilpasning og opplæring i bruk av sykkel som aktivitetshjelpemiddel

Dette er et spørsmål til deg om ditt barns deltagelse i en forskningsstudie som har som mål å fremme aktivitet, mestringsglede og sosial deltagelse i brukernes eget lokalmiljø. Studien gjennomføres som et doktorgradsprosjekt tilknyttet Beitostølen helsesportsenter og Universitetet i Oslo, og ditt barn er blant dem som er vurdert til å være aktuell for deltagelse.

## Hva innebærer prosjektet?

De som er aktuell for utprøving og tilpasning av sykkel som aktivitetshjelpemiddel er kandidater til deltagelse i studien. Brukeren vil bli spurt om å fylle ut et skjema før utprøving. Det samme skjemaet skal fylles ut etter at brukeren har hatt mulighet for ca. 3 måneders bruk hjemme. Under utprøving vil brukeren få festet en liten brikke øverst på ryggen, som vil måle hvordan hun/han sitter på sykkelen. Vi vil også måle hvor hardt hun/han tråkker/skyver mot pedalene. Prosjektleder skal intervjue et utvalg av deltagerne etter ca. 3 måneders bruk av en eventuell tildelt sykkel. Brukeren kan dermed bli spurt om å delta i et slikt intervju, med fokus på fremmende og hemmende faktorer for bruk. Dette intervjuet vil i tilfelle bli tatt opp på lydbånd. Du som forelder/foresatt kan delta på dette intervjuet hvis ønskelig.













## Mulige fordeler og ulemper

Ansvarlig for søknad om sykkel som aktivitetshjelpemiddel vil være den samme fagpersonen som det ville vært dersom brukeren ikke deltok i prosjektet. Det kan hende at utprøvingsseansen tar noe lengre tid, og at flere aktuelle sykler blir prøvd. Dette fører til en grundig vurdering av aktuelle sykler og mulige tilpasninger av disse.

Utprøvingen/tilpasningen skal ikke gå ut over annet behandlingstilbud, med mindre brukeren selv velger det.

Ved et eventuelt intervju, vil brukeren snakke med en voksen, ukjent person og samtalen vil bli tatt opp på lydbånd. Dette kan oppleves uvant for brukeren.

## Frivillig deltagelse og mulighet for å trekke sitt samtykke

Det er frivillig å delta i prosjektet. Dersom brukeren ønsker å delta, undertegner bruker og foresatt samtykkeerklæringen på siste side. Hun/han kan når som helst og uten å oppgi noen grunn trekke sitt samtykke. Dette vil ikke få konsekvenser for videre behandling. Dersom brukeren trekker seg fra prosjektet, kan hun/han kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom hun/han senere ønsker å trekke seg eller dere har spørsmål til prosjektet, kan prosjektleder Berit Gjessing kontaktes på <u>berit.gjessing@bhss.no</u> eller 95974111.

# Hva skjer med innhentet informasjon?

I prosjektet vil vi innhente og registrere opplysninger om navn, kjønn, alder, bosted og diagnose. Informasjonen som registreres skal kun brukes slik som beskrevet i hensikten med studien. Dere har rett til innsyn i hvilke opplysninger som er registrert og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter bruker til innsamlede opplysninger gjennom en navneliste. Informasjon vil bli lagret på et sikkert sted. Det er kun autoriserte personer knyttet til prosjektet som har tilgang til innhentet informasjon. Prosjektansvarlig og veiledere har alle taushetsplikt. Innsamlet informasjon vil bli slettet senest to år etter prosjektslutt.





# **Forsikring**

Ved deltagelse i prosjektet vil du være forsikret via pasientskadeloven.

# Godkjenning

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, saksnr. hos REK (20xx/yyy).

Med vennlig hilsen

**Berit Gjessing** Prosjektleder **Reidun Birgitta Jahnsen** Prosjektansvarlig





# Samtykke til deltagelse i studien

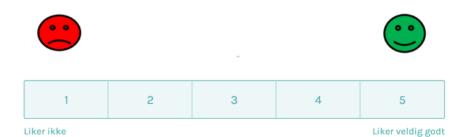
# Hva er best for meg?

Utprøving, tilpasning og opplæring i bruk sykkel som aktivitetshjelpemiddel

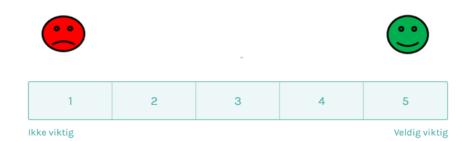
Jeg er villig til å delta i studien	
Sted og dato	Deltagers signatur
	Deltagers navn med trykte bokstaver
Som foresatte tili prosjektet	samtykker vi til at hun/han kan delta
Sted og dato	Foresattes signatur
	Foresattes navn med trykte bokstaver
Jeg bekrefter å ha gitt informasjon om prosjekt	ret
Sted og dato	Signatur
	Rolle i prosjektet
	- Probjement

syklet i løp	et av de siste	e fire månedene? *
svar på alle sp	oørsmålene)	
(gå til spørsn	nål 6)	
te har du sy	klet de siste	fire månedene?
ng i måneden	eller mindre	
ganger i måne	den	
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ganger i uken		
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amilie (foreldre	søsken)	
ndre slektninge		tanter, onkler, søskenbarn
enner		
ndre (instruktø	rer, støttekontak	t, assistent eller andre)
ar du oftest		rt, assistent eller andre)
		rt, assistent eller andre)
ar du oftest	t syklet?	ct, assistent eller andre)
	svar på alle sp (gå til spørsn te har du sy ng i måneden ganger i måne ng i uken ganger i uken r dag	svar på alle spørsmålene)  (gå til spørsmål 6)  te har du syklet de siste  ng i måneden eller mindre  ganger i måneden  ng i uken  ganger i uken  dag  r du oftest syklet sammen  amilie (foreldre, søsken)  ndre slektninger (besteforeldre, ndre)

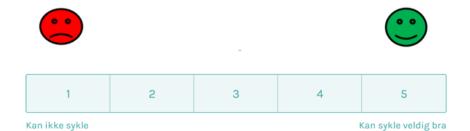
# Hvor godt liker du sykling?



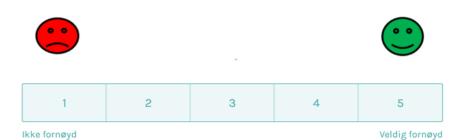
7→ Hvor viktig er sykling for deg? \*



Hvor godt synes du at du sykler nå? \*



Hvor fornøyd er du med måten du sykler på nå? \*



Dersom du har andre kommentarer til sykling, som du ikke har blitt spurt om, kan du skrive her: