BarnAs 1 - Development of an assessment tool for mapping activity preferences for children and adolescents (5-18) with disabilities

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Certificate of Authorship

I hereby declare that this submission is my own work and, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged. I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services, or nominee, for the care, loan and reproduction of theses, subject to confidentiality provisions as approved by the University.

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CHAPTER 1, INTRODUCTION AND BACKGROUND

1.1 Introduction

A main goal for health, social and pedagogical service providers in the field of paediatric rehabilitation is to optimize participation in different life arenas for children and adolescents with disabilities. Participation in preferred and enjoyable physical activities is essential for physical and social well-being (Hoogsteen & Woodgate, 2010; King et al., 2003; Majnemer et al., 2008) and gives children, and young people in general, a sense of belonging; it provides opportunities for them to fulfil their personal goals, and to develop and grow as individuals (Eime, Young, Harvey, Charity, & Payne, 2013). Physical activity is an essential part of child development, both in relation to health, and to the development of physical and social skills. These skills are important in interactions with peers in kindergarten, at school and during leisure time.

This thesis is about the validation of a questionnaire used with children and adolescents who have disabilities (CADs). It was originally developed in Norway, at a rehabilitation facility called Beitostolen Healthsports Center (BHC), which is described in detail later. In short, BHC provides ongoing care and rehabilitation for CADs and their families, through a system of support, education and live-in facilities. It is the site of a range of research projects, including questionnaire development for this specific population, on a variety of topics and research areas.

This first chapter of this thesis describes the background for making the choice to develop and validate an instrument for CADs with disabilities. It examines the importance preferences have in relation to participation in various physical and leisure time activities. The institution and the previous work with instruments for mapping preferences, choosing activities and setting goals also are described.

In the interests of clarity and accuracy, the whole thesis was initially written in Norwegian, and then I translated it into English. Translations were checked by a native Norwegian speaker who is bilingual in English.
1.2 Preferences and participation

The child’s participation in physical leisure activities occurs within a dynamic interaction between the child and the environment. The participation is driven by the child’s preferences for activities in combination with levels of maturity, and development of the activity competencies possessed by the child. Participation is also driven by the complexity of the social and environmental context in which the activity takes place. The World Health Organization (WHO) defines participation as a person’s involvement in a life situation (WHO, 2007). Children and adolescents with disabilities (CADs) are known to encounter restrictions to their participation in various activities, in kindergarten, school, and leisure time activities, due to both individual and environmental barriers (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; King et al., 2007).

For CADs, the child’s preferences (what a child prefers to do in relation to whatever is on offer) are the most important predictor of participation (Shields, Synnot, & Kearns, 2015). Preferences can be defined as the subjective elements of how people explain their participation (Skille & Østerås, 2011). Preferences are described as intrinsic factors that have relation to, and are consequences of, participation (Imms et al., 2017).

Preferences are established through past experiences of enjoyment when doing an activity, interaction with people who share the same values, and through attachment to certain places (Imms et al., 2017). Studies have shown that children with disabilities are less likely to prefer activities than children without disabilities (Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2014). There is a correlation between a person’s self-efficacy and preferences, and children with lower levels of self-efficacy can have fewer preferences for activities (Engel-Yeger, Hanna-Kassis, & Rosenblum, 2012). The child’s self-efficacy is influenced by previous experiences of success. One can assume that children with disabilities experience less success in physical activities, and there is evidence to show that children with disabilities meet restrictions on participation in various activities due to physical, social, and attitudinal barriers (Bult et al., 2011; King et al., 2007).
When considering implementing efficient interventions to optimize participation in physical activities, it is important to consider the complex interaction of individual characteristics, such as functional level and motivation, and physical, social and environmental factors. The interventions need to be family-centred, where children, youth, and their families are actively involved in the entire rehabilitation process (An & Palisano, 2014). Since preferences for activities are based on the child’s interests and will influence the child’s level of participation, it is important to consider a child’s activity preferences when planning an intervention. Consequently, it is essential to use valid and reliable instruments to capture the child’s preferences, and it is desirable that the child her/himself answers questions about his or her preferences.

Participation goals in rehabilitation interventions must be sufficiently challenging, neither too easy nor too hard to achieve, but provide a sense of manageability (Eriksson & Lindstrom, 2007). It is important that the goals are child/family determined and meaningful, since goal attainment and opportunities to make choices that enhance the intrinsic motivation to engage in a specific activity, and stimulate beneficial rehabilitation outcomes (Abuhamdeh & Csikszentmihalyi, 2012; Deci & Ryan, 2000).

There are few empirical studies that describe the contextual and methodological features considered when implementing interventions to improve participation in leisure activities of CADs. The reason might be informal and non-standardized processes for goal setting, implementation of rehabilitation strategies, and the lack of adequate ways of evaluating outcomes of participation.

1.3 Setting for this study

The Beitostolen Healthsports Center (BHC) is a residential facility that offers rehabilitation services based on a family-centred approach for children and youth with a range of disabilities. BHC is located in a small mountain village named Beitostolen situated in the eastern part of Norway. The Center is recognized as an official part of the national specialist health service system in physical medicine and rehabilitation, and is funded by National Health Service with no cost for users.
The rehabilitation program at the Center is based on the vision of Adapted Physical Activity (APA). The term was introduced in 1973 by the founders of the *Fédération Internationale de l’ Activité Physique Adaptée*. “Healthsports” is the commonly used term for APA in Norway, from whence the name of the institution derives. Appendix 1 contains pictures from the daily life at the Center.

The objective of BHC is, by means of physical, social and cultural activities, to help persons with mainly physical disabilities achieve optimal functional independence, and the ability to be active and participating in daily life. The Center is recognized as an official part of the national specialist health service system in physical medicine and rehabilitation in Norway. There are also close relationships with voluntary organizations within sports and environmental activities as part of the follow up strategies of the activities at BHC. The users of the Center are admitted by application from a medical doctor, also with recommendations and information from other relevant professionals. A stay at the Center, usually 3-4 weeks, is paid for in full by the Norwegian Social Security System. This also includes guides, helpers or parents who are needed for successful participation in the programs.

A stay at BHC serves as one important part of a total rehabilitation "chain", most commonly at the latter part of rehabilitation. The main focus of the stay is on provision of a wide spectrum of activities, in spite of, rather than because of, a disability. The activities offered, to some extent, reflect the Norwegian activity culture, with great emphasis on outdoor activities.

APA (Adapted physical activities) encompasses participation in many kinds of settings (inclusive, partially inclusive, and separate) throughout the lifespan. Subspecialisations of APA may include physical education (PE), sports, recreation, and rehabilitation. APA has a strong focus on a cross-disciplinary approach.

At BHC, goals have been defined by CADs and their families by using the Canadian Occupational Performance Measure (COPM) (Dedding, Cardol, Eyssen, Dekker, & Beelen, 2004). Following a rehabilitation stay at the Center, CADs set physical activity goals themselves using Goal Attainment Scaling (GAS) (Steenbeek, Ketelaar, Galama, & Gorter, 2008). These goals are meant to be achieved and followed up within their own community context, with follow up after three months. However, these two individualized instruments (GAS and COPM) can be too
abstract and not user-friendly for CADs. *BarnAs 1* (in English “Children’s 1”) is an instrument designed so that CADs can self-report their activity preferences with minimum guidance.

In a doctoral project (Nordtorp, Nyquist, Jahnsen, Moser, & Strand, 2013), the Children’s Assessment of Participation and Enjoyment (CAPE) and the Preferences of Activities in Children (PAC) were used for mapping CADs’ enjoyment and participation profiles. The participation profile contains variables, such as diversity of activities, frequency, enjoyment and contextual factors, including where and with whom the activities were performed. Translation into Norwegian and reliability for mapping and evaluation was conducted at BHC (Nordtorp et al., 2013), and showed satisfactory results for clinical use of the Norwegian version. However, because of restrictions put in place by the publisher, the Norwegian version could not be widely disseminated.

Based on extensive clinical use, the scaling of the original version also proved to be too difficult to understand for many of the children without substantial help and guidance from parents or health personnel. The instrument is nearly 15 years old, and many of the current activities in which CADs now participate are missing, for example, martial arts and virtual reality training and gaming. There were also few winter activities, which are particularly important in Norway. Therefore, there was a need for a modified, updated and validated instrument to evaluate preferences for participation in activities of CADs in a Norwegian habilitation context.

*BarnAs 1* is a Norwegian assessment tool under development that aims to assess preferences of physical leisure activities among CADs, and which environmental factors that promote or prevent them from performing activities. An evaluation of the validity of *BarnAs 1* is the subject of this current study.

### 1.4 Aims

The aim was to develop, validate and implement a new web-based measure of children’s preferences for physical activities, *BarnAs 1*. It also tested the instrument’s content validity and feasibility.
1.5 Objectives

1. To gain knowledge about how service providers can optimize CADs’ participation in physical leisure activities by developing and applying tools which identify children’s own preferences; and

2. To develop a valid instrument that is easy enough to understand and answer by CADs so they can answer it themselves, with minimum guidance from adults.

1.6 Scientific importance and implication for practice

This project seeks to ensure that BarnAs 1 will provide clinicians and researchers at BHC, and other service providers in specialist and primary health care settings, as well as in pedagogical settings, with a user-friendly instrument for measuring CAD’s preferences for activities. The results from this project will clarify important factors contributing to participation, and these will assist service providers in their work of setting realistic child/family determined goals that can be realized at home and in the local community. The identification and evaluation of effective strategies of goal attainment can enhance the probability of success in any future intervention studies (Leon, Davis, & Kraemer, 2011). Knowledge of essential elements for goal attainment will also allow health, social and pedagogical service providers in the field of paediatric rehabilitation to be able to design intervention models more successfully in further research.

The project will ensure that BarnAs 1 will be applicable and efficient when used in a variety of (re)habilitation units and in community settings. Thus, the BarnAs 1 will contribute to evidence based (re)habilitation services and hopefully enhance participation in physical and leisure activities in our target groups.
1.7 Research questions

Q1 Are there any relevant instruments for mapping preferences for activities among children and adolescents with disabilities (CADs)?

Q2 Does BarnAs 1 have content validity?

Q3 What activities are important to include in the BarnAs 1 given CADs’ preferences?

Q4 How applicable is the web-based BarnAs 1?

Q5 Can the web-based BarnAs 1 be easily connected to existing data collection programs and patient administration systems?

1.8 Conclusion

Preferences are an important mediator for a person’s participation level. Therefore mapping a person’s preferences is important when the goal is to increase the person’s participation in physical and leisure time activities. In recent years, there has been an increasing focus on user participation in public health services. To make this influence real for CADs, it is important to hear their voices, and not just the voices of their guardians or their “helpers”. This makes an instrument that CADs can understand and answer themselves necessary. The next chapter will describe a literature search for possible instruments for mapping preferences for physical activities among CADs.
CHAPTER 2, LITERATURE REVIEW

2.1 Introduction

This chapter describes the literature review step by step, and the methods used, how the search was undertaken and with which search words. The results are presented and discussed before the conclusion of the review.

The goal of this review was to find out if there are any validated instruments available for mapping preferences for activities by CADs. Based on experience from clinical practice with CADs, few instruments for mapping their preferences were available, demonstrating a lack of such measures. A systematic search was undertaken to investigate the availability of instruments that can be used to assess preferences for activities of CADs aged 5–18 years.

The age range (5-18 years), was chosen as it is a time for children to become competent in a range of activities, and then gradually become autonomous in participating in life situations (Pehoski & Henderson, 2006). If any instruments were found, another important goal for the literature review was to assess their psychometric properties and clinical utility. The results of the review provide a useful guide for selection of appropriate measures to evaluate activity preferences.

2.2 Inclusion criteria

The inclusion criteria were set according to important features that are needed in such an instrument. These were:

1. The target population included CADs aged 5-18 years;
2. The instrument was used in field-based studies involving CADs;
3. The study involved both a dimension of activity and a dimension of preferences, and”
4. CADs should be able to understand and complete the instrument themselves.
After the first search, it became evident that these criteria were too narrow. Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children (CAPE/PAC) – (King, 2005) were the only instruments that partly met the criteria, which were then revised to include articles about mapping activities for CADs, with an extra dimension containing enjoyment and/or preferences. After this search was conducted, the instruments found were evaluated according to the criteria as they represent the practical needs that the instrument is meant to cover.

### 2.3 Methods

An initial search was done to find the relevant search words, index words and free text words. A comprehensive search was conducted in PubMed, Medline and Cochrane Library. Clearly defined inclusion and exclusion criteria were set. A PRISMA flow chart was developed as a basis for the review. A review of the search was done by two independent researchers based on an adapted PRISMA chart (Moher, Liberati, Tetzlaff, Altman, & Group, 2009), to ensure that no relevant instruments were left out. The instruments that met the inclusion criteria were further examined. Both independent researchers concluded with the same findings, and located the same instruments.

Search mesh terms in PubMed were: disabled persons (includes sub-category of disabled children), motor skills disorder, adolescent (=13-18 years), child (=5-12 years), paediatrics, motor activity, patient preference, leisure activity. Mesh terms covering the same sub-categories were used in the other databases.


Figure 1, a modified PRISMA Flow Chart (Moher et al., 2009), demonstrates the relevant articles found and the screening process that followed. A total of 78 relevant articles were located; amongst these, 22 duplicates were removed. All abstracts were
read for the remaining 56, leading to the removal of 29 articles due to lack of relevance, as they did not include validated instruments or included only peer-reported questionnaires. 27 articles were read in full text, 12 more were removed, as they had no relevant information not covered by other articles. Five instruments were identified based on the remaining 15 articles. See Figure 2.1. Figure 2.2 shows the included articles and whether they really examined preferences.
Figure 2.1, Prisma Flow chart demonstrating the search and screening process.

Records identified through database searching (n = 74)

Additional records identified through other sources (n = 4)

Records after duplicates removed (n = 56)

Records screened (n = 56)

Records excluded, lack of relevance (n = 29)

Full-text articles assessed for eligibility (n = 27)

Full-text articles excluded, did not fulfil the criteria (n = 12)

Studies included for closer review of the instruments (n = 15)
## 2.4 Results

**Figure 2.2. The included articles and whether they really examined preferences**

<table>
<thead>
<tr>
<th>Studies</th>
<th>Instruments</th>
<th>Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Revalidation of the Physical Activity Enjoyment Scale (Zhou et al., 2014)</td>
<td>PACES*</td>
<td>No preferences</td>
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<tr>
<td>2. Physical Activity Enjoyment Scale: Two Validation Studies (Kendzierski &amp; DeCarlo, 1991)</td>
<td></td>
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<tr>
<td>3. Physical Activity Enjoyment Scale short form--does it fit for children? (Paxton et al., 2008)</td>
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<tr>
<td>4. Measuring enjoyment of physical activity in adolescent girls (Motl et al., 2001)</td>
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<tr>
<td>5. Factorial validity and gender invariance of the physical activity enjoyment scale (PACES) in older adolescents (Dunton, Tscherner, &amp; Rodriguez, 2009)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. CAPE/PAC Children's assessment of participation and enjoyment and preferences for activities of children (Gillian King, 2005)</td>
<td>CAPE/PAC*</td>
<td>Preferences</td>
</tr>
<tr>
<td>10. Leisure activity preferences for 6- to 12-year-old children with cerebral palsy (Majnemer et al., 2010)</td>
<td></td>
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<tr>
<td>11. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC (G. A. King et al., 2007)</td>
<td></td>
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</tr>
<tr>
<td>12. Validation of the Physical Activity Questionnaire for Older Children (Kowalski, Crocker, &amp; Faulkner, 1997)</td>
<td>PAQ-A**** PAC-C</td>
<td>No preferences</td>
</tr>
<tr>
<td>13. Convergent Validity of the Physical Activity Questionnaire for Adolescents (Kowalski, Crocker, &amp; Kowalski, 1997)</td>
<td></td>
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<tr>
<td>15. The validity and reliability of a home environment preschool-age physical activity questionnaire (Pre-PAQ) (Genevieve M. Dwyer, Louise L. Hardy, Jennifer K. Peat, &amp; Louise A. Baur, 2011)</td>
<td>Pre-PAC*****</td>
<td>No preferences</td>
</tr>
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</table>

*Physical Activity Enjoyment Scale, **Activities Scale for Kids, ***Children’s Assessment of participation and enjoyment/ Preferences for Activities in Children, Physical Activity Questionnaire – Adolescents/Children****, Preschool-age physical activity questionnaire*****
2.5 Evaluation of instruments according to the original inclusion criteria

2.5.1 The Activities Scale for Kids (ASK) (Young et al., 2000)

About the instrument:
The ASK is a self-reported measure of disability for children between the age of 5 and 15 years. It is developed in two versions, the original version, the Activities Scale for Kids (ASK), and the Activities Scale for Kids performance version (ASKp.). The original version measures what the child could do during the previous week (capability), while the performance version measures what the child did do (performance).

The ASK contains 30 items that are aggregated into one overall sum score. There are seven sub-domains: personal care, locomotion, dressing, other skills, play, standing skills and transfers. The ASK reflects the children’s perspectives of disability and it provides the option of examining performance and/or capability. It is a useful instrument for exploring the nature of children’s activity limitations. The ASK has excellent reliability (ICC=0.97) and the validity was demonstrated by a correlation of 0.81 (P<0.0001) with parent-reported Childhood Health Assessment Questionnaire (CHAQ) scores; a significant difference in scores according to clinicians’ global ratings of disability (P<0.0001), and a correlation of 0.92 (P<0.0001) with clinician observations (Young et al., 2000). The Childhood Health Assessment Questionnaire (CHAQ), is an instrument originally made to assess health status in children with juvenile rheumatoid arthritis (Klepper, 2011). In the process of validating the ASK, the CHAQ was also sent out and answered by all the participants. Completed forms from both the instruments were returned to the researchers for analysis and comparison (Young et al., 2000).

Evaluation in relation to inclusion criteria:
The ASK and the ASKp are focused mainly on daily activities and not on leisure time activities or physical activities. They lack the desired dimension of preferences for this current study. Palisano et al. have used the ASKp to show that the motor abilities of adolescents with cerebral palsy (CP) influenced their participation in physical activities (Palisano, Copeland, & Galuppi, 2007).
2.5.2 Physical Activity Enjoyment Scale (PACES) (Kendzierski & DeCarlo, 1991)

About the instrument:
The PACES is a survey instrument used to measure enjoyment of physical activity. The instrument consists of 18 items assessing exercise enjoyment. The instrument is also available in a shorter version, Physical Activity Enjoyment Scale Short Form (Paxton et al., 2008). The instrument’s validity has been tested in measuring enjoyment of physical activity in adolescent girls (Motl et al., 2001), and another study examined the factorial validity and gender invariance in older adolescents (Dunton et al., 2009).

A revalidation of the instrument was done in 2014 (Zhou et al., 2014), the most recent validation. They found, through confirmatory factor analysis, that the construct validity of the original scale and were not within acceptable range (that is, goodness-of-fit index = 0.72, adjusted goodness-of-fit index = 0.64, and root mean square error of approximation = 0.12). The scale was revised, and the revised scale, consisting of two domains, showed acceptable validity and reliability. Cronbach’s alpha for the entire revised scale was 0.96, while the alpha for the domain of perception and antecedent of enjoyment was 0.9 and 0.95 respectively. A Cronbach’s Alpha value of 0.70 and above are considered acceptable (Taber, 2018).

Evaluation in relation to inclusion criteria:
PACES is validated among most of the target age groups. It does not have the properties to measure new activities that have not been tried yet. It is also too difficult for the younger children to self-report.

2.5.3 Physical Activity Questionnaire for Adolescents (PAQ-A) (Kowalski, Crocker, & Kowalski, 1997)

About the instrument:
This is a modified version of the Physical Activity Questionnaire for Older Children (PAQ-C) (Kowalski, Crocker, & Faulkner, 1997). Both these instruments measure physical activities during the previous seven days. There are nine different questions
that ask about the type of activity, what the respondent has done at lunchtime, about physical activity after school, in the evening, on the weekend, and how much of the participant’s spare time was used for physical activity. There is also one question about sickness during the past week. The instruments were modified and validated in 2016 (Aggio et al., 2016). This process revealed that the original instruments were unrepresentative for English youth, and that item comprehension varied. After contextual and population/cultural-specific modifications were made, the modified instruments had acceptable internal consistency (α=0.72) and test-retest reliability (ICC= 0.78).

Evaluation in relation to inclusion criteria:
There are no questions regarding preferences for activities, neither before nor after doing the activities. In addition, the questionnaire is difficult for children to fill out on their own.

2.5.4 Preschool age physical activity questionnaire (Pre-PAQ) (Dwyer et al., 2011)

About the instrument:
This instrument is a three-day activity questionnaire, which is designed to measure habitual physical activity and sedentary behaviour in the child's home environment. Pre-PAQ is meant to be used during one week-day and two weekend days. It has a list of activities typical for the age group and asks YES or NO related to each activity; if yes, the time spent on the activity also is recorded. It also has a section measuring parents’ level of physical activity. The instrument has acceptable validity and reliability, where the answers ranged from 0.31-1.00 for continuous measures and from 0.60-0.97 for categorical measures (Dwyer et al., 2011).

Evaluation in relation to inclusion criteria:
There are no questions regarding preferences for activities, neither before, nor after, doing the activities. The instrument is designed for parents to fill out, and it is long with some complicated questions. Thus, it does not fulfil the inclusion criteria.
2.5.5 Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children (CAPE/PAC) (King, 2005)

About the instrument:
The CAPE is a self-report measure of participation for CADs aged from 6-21 years. It includes both formal and informal domains, and measures five activity types: recreational, active physical, social, skill-based and self-improvement (King, 2005), that are again divided into 49 specific activities. The CAPE assesses five dimensions of children’s participation in recreation and leisure activities (diversity, intensity, location, companionship, and enjoyment). The conceptual strengths of the CAPE include its measurement of multiple dimensions of participation (Imms, 2008). CAPE also measures the enjoyment of an activity on a scale from 1-5.
The PAC (King, 2005) is used to assess children’s self-reported preferences for recreational, active physical, social, skill-based and self-improvement activities. It is widely used among CADs, for example, to describe leisure activity preferences for 6-to 12-year-old children with CP (Majnemer et al., 2010). Activity preferences are scored on a three-point scale also represented by smileys (1 = would not like to do at all, 2 = would sort of like to do, 3 = would really like to do). The PAC is translated into various languages and validated in various contexts and populations; it has, for example, been validated amongst children with high functioning autism (Potvin et al., 2013). The Norwegian version demonstrates both internal consistency and sufficient test-retest reliability and content validity; the alpha values for internal consistency varied between 0.53 and 0.87 for the CAPE and between 0.75 and 0.93 for the PAC. ICC was from 0.49 to 0.83 for the CAPE and 0.85 for the PAC (Nordtorp et al., 2013).

Evaluation in relation to inclusion criteria:
CAPE measures participation in activities and how much the various activities are enjoyed. PAC is the only instrument found that to a certain extent matches all the inclusion criteria. The only criterion that is not fully met is: CADs should be able to understand and report in the instrument themselves. While this is possible for the older children and adolescents, PAC is too long and
complicated for the younger children in the target group. Many of the activities are no longer relevant for today’s CADs as the instrument is over 12 years old. In addition, there are relevant activities in a Norwegian context that are missing, particularly winter activities.

2.6 Discussion

In this review, five potential instruments were identified for mapping activity preferences of CADs. None of the instruments fully matched all the needs described in the inclusion criteria. Most of them met only two. ‘Preferences’ was the criterion that few of the instruments included. ‘Preference’ is not a well-defined term in relation to this setting. The PAC (King, 2005) was found to be the only instrument that measured preferences by self-reporting in the target group. The other instruments relied on reporting by health personnel or guardians, making it more uncertain if the CADs’ own voices were heard or not.

There seems to be no or little focus on instruments where CADs’ own voices are heard. When preferences are described mainly by observing adults, this may leave room both for interpretation and misunderstanding. The instruments that met most criteria - the CAPE and the PAC (King, 2005), are widely used all over the world. The PAC has been validated in many different cultures and languages. There is a need for an instrument that is able to measure CADs’ preferences in a valid and reliable way. However, the PAC is extensive, somewhat dated, and lacks many of the activities in which CADs participate or could participate in today. In a Norwegian context, a diversity of winter activities is missing. The wording of the questions asked in PAC is also complicated for small children; “If you could do anything in the world, would you …..?” (King, 2005). In our clinical practice at BHC, we find this to be too abstract for our participants. The instrument is not digital, and requires much patience and explanation for CADs to fill out.

Since the PAC will not be published in Norway, a modified and digital version has been trailed in collaboration with the author of PAC, (King, 2005). This instrument is called BarnAS 1 (Children’s 1) (Appendix 1) Instead of drawings, photographs of relevant activities in the rehabilitation setting at BHC are used. The photographs show alternative ways of performing the activities, for example, alpine skiing can be
performed standing or sitting. This is important, as the CAD might not be aware that there is the possibility of doing the activities provided the needed adaptations are made. The children are asked a simple question one month before arriving at BHC; “If you had the possibility, would you like to try this activity?” The answer alternatives are the same as in the PAC, three different smileys, one negative, one neutral and one positive smiley.

Two other Norwegian rehabilitation centres have started to test this modified instrument for activity preferences, with different target groups and activities. The BarnAS 1 has the possibility to be developed into a generic instrument where the activities can be changed according to the context. A feasibility study in three Norwegian rehabilitation centres will be conducted, and if this proves favourable, further investigation of psychometric properties will be conducted in the different contexts.

2.7 Limitations of the literature review

One limitation of this literature review might be my, and my co-researchers’ previous knowledge of the field, and any prejudices of expectations to which this might lead. The hypothesis before undertaking this review was that there were no other relevant instruments available other than the PAC. This might have led to the researchers seeking to narrow the search when selecting search words and search strategies. Another limitation is the reliance of the published research found based on the search strategy outlined in the methods chapter of this review, and not searching outside the main known databases. In addition, because of time and resource constraints, we were unable to search the grey literature.

2.8 Conclusion

The systematic review of the literature was conducted under recognized guidelines for such studies and used a PRISMA flowchart. We defined inclusion and exclusion criteria, search terms and methods and the resulting search provided five studies for inclusion.
The review has confirmed that there is a lack of eligible instruments for mapping activity preferences in CADs in Norway, especially an instrument reported by the children themselves. Thus, there is a need for development of a modified and feasible instrument to fulfil this aim in the target group. There is also a need for a further examination of the term ‘preferences’ in this group and how preferences relate to participation and the outcome of rehabilitation. The results of the literature search was presented as a poster presentation at the EACD 2017 in Amsterdam, see Appendix 2. An article has also been sent for publication based on this review, see Appendix 7.

The next chapter will describe the methodology, and methods used for the development and validation of the BarnAs 1, describing both the participants in the study and how the study was conducted.
CHAPTER 3, METHODS

3.1 Introduction

This chapter explains the methods used, and how they were employed during the different parts of the study, both for the data collection and the analysis of the data. The study consists of three parts, with each part building on the previous ones, and uses a multi-methods design. The first part uses a quantitative design while the second and third parts use qualitative techniques.

The first part is a retrospective study based on answers given to the pilot version of BarnAs 1 (in English “Children’s 1”) by 341 CADs who participated in a rehabilitation stay at BHC in 2015. The second part contains interviews with the multidisciplinary teams at BHC in 2017, while the third part consists of interviews with six CADs who were at BHC in June 2018. See Figure 3.1 for an outline of all the parts of the study, and how the previous parts influenced the further study. The parts, and the methods used are described consecutively later in this chapter.

This chapter outlines the methodology, including theoretical frameworks on which the study is based, and then describes the methods used to undertake the study.

3.2 Methodology

Both quantitative and qualitative methods were employed. The study was a pilot study of an existing tool, and both methods informed development and testing of the tool for this particular population. As such, it is better to be called a ‘multi-methods’ study; ‘mixed methods’ requires a strong framework to ensure the analysis of the quantitative and qualitative arms are interlinked and relevant (Swallow, Newton, & Van Lottum, 2003). The current study, as a pilot study, did not use such complex methods; however, it may be possible in later studies to develop a mixed methods framework for more in-depth analysis of the needs of the children and families using the service.

The decision to use a qualitative approach or quantitative approach is based on the research questions and hypotheses, and the theoretical framework on which the study
is based. (Schneider, 2013). Quantitative research derives from the positivist approach and includes the testing of causal relationships, objective observation, with potential prediction of outcomes (Schneider, 2013). Quantitative research employs logical processes to test hypotheses. Hypotheses derive from the research questions to be answered. Quantitative research is characterized by the fact that the researchers are using numbers, frequencies and calculations. Quantitative research is often concerned with behaviour, begins with hypotheses and uses generalisations (Schneider, 2013).

Qualitative research is interpretive, it describes, explores, and examines in reality; and while research questions are the basis for a qualitative research project, this type of research does not always require hypotheses to be tested (Whitehead, 2010). Qualitative research commonly includes interviews, conversations, storytelling, and other methods of data collection that may not necessarily require the counting and use of numbers that quantitative research does (Shields & Twycross, 2003). In qualitative research, numbers are absent and (usually) words are used. It is often concerned with meaning and includes questions from data. Qualitative research is able to focus on behaviour in situations that naturally occur (Schneider, 2013).

3.3 Study design

Design, understood as a research project’s main pattern, explicates how different elements are incorporated into a study, and the relationship of the elements and timeline of the execution of the project. This study uses a multi-methods, cross-sectional, observational design. Observational designs are non-experimental, are used to explore situations as they naturally occur, and where the phenomena being studied cannot be incorporated into an experimental design (Shields & Watson, 2013). Cross-sectional studies measure data at one point in time, and, as in this case, can include both qualitative and qualitative data (Shields & Watson, 2013).

Before the design is developed, some important questions have to be raised. In what is described colloquially as an armchair walkthrough technique (Morse, Barrett, Mayan, Olson, & Spiers, 2002), questions such as, what is the purpose of the study?, On whom can the study be done based on the research questions?, What is possible? What constitutes suitable selection of participants; how are the data gathered?, and
which techniques and analysis can be used, are considered. These considerations were implemented in planning the current study, and gave the foundation for the use of the chosen design.

3.4 Theoretical framework

Theoretical frameworks underpin the theories that are employed to test the questions, hypotheses and assumptions inherent in the research (Schneider, 2013). This study, as a pilot study, calls on theoretical frameworks underpinning the practices of piloting and testing projects before the full project is implemented. Theoretically, a pilot study provides the opportunity for testing the feasibility, processes, safety, interpretations, and other aspects of the proposed project (Leon et al., 2011). However, a pilot study does not test hypotheses, nor does it try to test the research question itself. Importantly, the main reason to do a pilot study is to make sure that the project proposed can be carried out ethically, safely, efficiently, and can attain the desired results. That is not to say that the results will be found in the pilot study, rather, it demonstrates the feasibility of the study to produce the types of results necessary to answer the research questions. It is also an opportunity to see if the study makes sense to the target population, and those supporting them (Schneider, 2012; Winch, 2008).

A pilot study is a precursor to a full study, in which the techniques, tests and instruments, and procedures to be used in the full study are tested. A pilot study can be a minor version of the full-scale study, or, as it is in this study, a pre-testing of an instrument in the form of a questionnaire. Pilot studies are a crucial element of a good study design (Van Teijlingen & Hundley, 2002). Feasibility studies are often used to answer the question: can it work? Feasibility studies are used for many purposes, such as to evaluate a participant response to an intervention. They assess the data collection procedures, and “user friendliness” of a questionnaire (Orsmond & Cohn, 2015).
3.5 Content and face validity

Part of a pilot study is to test content validity of its tools. Content validity is used to investigate whether the different items on a test are really measuring what the test seeks to measure. Content validation seeks to assess this quality in the items that the test contains. (Salkind, 2010).

One of the aims of this study is to ensure that the questionnaire, BarnAs 1, measures what it needs to measure, and that it is applicable, relevant, and easily used by the target population – in this case children and families using the BHC facilities. This is called content validity, and face validity (Twycross & Shields, 2004). Face validity is determined when experts in the relevant field conclude that the questions on the questionnaire are measuring what they meant to measure. Similarly, content validity determines, in a more in-depth way than face validity, that the questions work and are relevant to the particular research question (Polit, 2001, Polit & Beck, 2006).

Content validity can be tested by relevant experts who can judge that the questions and constructs in the questionnaire are not just relevant to the participant population, but are also drawn from existing literature and what is known about the topic (Polit & Beck, 2006).

3.6 Methods

This is a content validity and feasibility study of a new web-based measure of children’s preferences for physical activities - BarnAs 1. BarnAs 1 is an instrument that was originally designed by the multidisciplinary team at BHC. BarnAs 1 is based on a 14-year-old Canadian instrument, the PAC (Preferences of Activities in Children) (King, 2005). The pilot version of BarnAs 1 was created prior to this study; the processes of the pilot version will be briefly described later in this chapter.
3.7 Significance of the study

The main goal at BHC is to optimize lifelong activity and participation for children with disabilities in their local environment (Dalen, Nyquist, Saebu, Roe, & Bautz-Holter, 2013). The intervention at the BHC is established on, and grounded in, principles of adapted physical activity (Hutzler & Sherrill, 2007). The rehabilitation program is based on the vision that children with disabilities should be able to participate in their preferred physical activities by changing the characteristics of the task and/or environment. Following the rehabilitation period, the children/adolescents together with the therapists set physical activity goals by using Goal Attainment Scaling (GAS) (Steenbeek et al., 2008), and The Canadian Occupational Performance Measure (COPM) (Law, 1991). However, experience has taught the health and social care professionals at BHC (“professionals”) that these two individualized instruments (GAS and COPM) can be too abstract and not user-friendly for the child. Further, in the process of identifying relevant goals, a measure of the child’s preferences for physical activities has been missing. *BarnAs 1* is a self-reporting assessment tool designed to be easy for children with disabilities to respond to with minimum guidance.

3.9 Development of the pilot version

This section will describe how the pilot version of *BarnAs 1*, used in the retrospective study in Step 1, was developed at BHC. Figure 3.1 illustrates the steps used in the study.
Figure 3.1, an outline of the entire research process

The research process:

**Trigger Study:**
Study by Nyquist (2012) explored CAD’s activity preferences and promoted a wider review of physical activity measure instruments.

**Literature review**
Of tools to determine the enjoyment and participation of CAD’s in physical activity (Chapter 2)

**Part 1: Retrospective Study**
Pilot study of the BarnAs1 with 341 CAD’s.
Descriptive statistics with frequency calculations employed. Focus on assessing the respondent understands interpretation and evaluation of the various activities on the Pilot BarnAs1 tool, and how to answer using smileys

**Part 1: Results**
Analysis by descriptive statistics with frequency calculations. 17 activities seen as popular. 2 activities not ranked as very popular.
Instrument (BarnAs1) was easy to use and well understood. Some small difference between age groups and gender. Helped establish questions for Step 2 and 3 to follow.

**Part 2: Group Interview with Professional therapists at BHC.**
Three separate group interviews with Professional Therapists at BHC (total n = 8).
Interviews lasted approx. 30 minutes / conducted in Dec 2017 / Jan 2018.

**Part 2: Results**
BarnAs1 easy to understand and relevant in terms of the majority of activities. Too many questions about snow/ice activities (one removed).
Missing questions about virtual reality / sensor-based computer games.

**Part 3: Interviews with individual CAD is about the revised version of BarnAs1.**
Individual interviews with 6 CAD’s (aged between 5 – 17 / both genders / interviews recorded on and then transcribed verbatim).
Conducted in June 2018

**Part 3: Results**
Interviews were analysed with Thematic Analysis and Systematic Text Condensation (Giorgi, 1985). Smiles were well understood. No activities missing and relevant activities included. Photos well understood some modifications needed.
Results grouped in three code groups identified:
1. Participation in activities
2. Understanding of the instrument
3. How to answer the instrument and how to make choices
The pilot version was based on an earlier PhD project at BHC (Nyquist, 2012), which investigated the process of identifying relevant physical activities to be included in the new measure, by reviewing previous COPM-goal activities of 149 children with disabilities. These individualised physical goals were determined for each child by using the COPM when the children arrived at BHC before the intervention period started, and were considered highly relevant for the children.

3.10 Development of the pilot version of BarnAs 1

Using these data as a guide, a list of relevant physical activities based on the children’s most frequent COPM goals were discussed with team leaders at BHC to ensure that no relevant activities were missing. The team leaders consisted of six physiotherapists and seven sport pedagogues who were highly experienced in working with children with special needs. The team leaders were often responsible for the goal setting procedure together with the child.

3.11 The retrospective study

In the retrospective study, the web-based pilot version of BarnAs 1, including the 19 activities, was tested, see Figures 3.2 and 3.3 for the introduction page of the questionnaire and a list of included activities. Three weeks before they arrived at BHC, the children were sent a four digit ID number and password, and asked to log in to the website www.barnas.bhss.no where they answered the questionnaire electronically.
Hello!!

Below we will tell you what to do to complete the form:

1. Go through each activity that is shown by looking at the pictures and reading the text that belongs to each picture.
2. Remember, there are no right or wrong answers.
3. You answer by clicking on the answer that is right for you.

Example of an answer:

![Smiley faces: Ikke lyst (don't want), Kanskje lyst (maybe want), Veldig lyst (really want)]

(Original picture from the questionnaire. The text from red to green translates: don’t want, maybe want, really want.)

Guidance for guardians:

1. Go through each activity that is shown by looking at the pictures and reading the text that belongs to each picture.
2. If the child needs assistance ask the child “(If you had the chance) how much would you like to do the activity shown in the picture?”
3. Always let the child try to answer first, before offering assistance.
4. Remember, there are no right or wrong answers.
5. You answer by clicking on the option that is right for the child, or reflects the child’s response.
### Figure 3.3: List of activities in the questionnaire

How much would you like to?

<table>
<thead>
<tr>
<th>Question nr</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pool?</td>
</tr>
<tr>
<td>2</td>
<td>Ride/drive tend to horses?</td>
</tr>
<tr>
<td>3</td>
<td>Bicycle?</td>
</tr>
<tr>
<td>4</td>
<td>Activities on wheels?</td>
</tr>
<tr>
<td>5</td>
<td>Practice Wheelchair techn.?</td>
</tr>
<tr>
<td>6</td>
<td>Climb?</td>
</tr>
<tr>
<td>7</td>
<td>The Gym?</td>
</tr>
<tr>
<td>8</td>
<td>Individual sport/activity?</td>
</tr>
<tr>
<td>9</td>
<td>Team sports?</td>
</tr>
<tr>
<td>10</td>
<td>Move to music?</td>
</tr>
<tr>
<td>11</td>
<td>Play/play games outdoor?</td>
</tr>
<tr>
<td>12</td>
<td>Go/roll for a trip?</td>
</tr>
<tr>
<td>13</td>
<td>Orienteer?</td>
</tr>
<tr>
<td>14</td>
<td>Do outdoor activities?</td>
</tr>
<tr>
<td>15</td>
<td>Do water activities outdoors?</td>
</tr>
<tr>
<td>16</td>
<td>Play in the snow?</td>
</tr>
<tr>
<td>17</td>
<td>Activities on ice/snow?</td>
</tr>
<tr>
<td>18</td>
<td>Going skiing/ski-pigging?</td>
</tr>
<tr>
<td>19</td>
<td>Alpine skiing?</td>
</tr>
</tbody>
</table>

#### 3.11.1 Participants

There were 431 eligible children who took part in a rehabilitation stay at BHC in 2015, and 341 children (79%) participated - 145 girls and 196 boys, aged between 5 and 18 years (mean age 11 years).

#### 3.11.2 Data collection

A four-digit ID number and password to log in to the website www.barnas.bhss.no was sent out to all CADs between the ages of 5 and 18 years who were to take part in a rehabilitation stay at BHC in 2015. This was done about three weeks before they...
arrived at BHC. One reminder was sent after two weeks if they had not responded. On the website, they answered the pilot version of BarnAs 1 electronically. The answers were entered into a database at BHC and were identified by ID numbers only.

3.11.3 Time frame
Questionnaire data were collected from the 1st of January 2015 until the 31st of December 2015. Data analysis was completed in September 2017 and dissemination begun.

3.11.4 Analysis
Descriptive statistics, including frequency calculations were used to report the responses from the 341 web-based forms of BarnAs 1 regarding the CADs’ preferences for the various activities, and to see if there were differences in preferences between the sexes, and between different age groups. The sample was divided in three age groups; 6-9 years, 10-13 years and 14-17 years. Statistical analyses were performed by using the Windows software program Excel for Windows, 2016 version.

The children had to rate how much they would like to try the different activities from 1 to 3 where 1=don’t want, 2=maybe want and 3= really want to try. At the end of the web-based questionnaire, the child had an opportunity to enter a free text comment regarding whether they missed any activities, or had something else they wanted to add. An email address was provided in case the respondents had any questions about how to respond to the web based questionnaire.

3.12 Group interviews
Three group interviews were conducted with therapists from the different teams working with children at BHC to investigate their experiences with using the pilot version of BarnAs 1.
3.12.1 Participants
The respondents were three physiotherapists and five sports pedagogues. The sports pedagogues are gymnastic teachers with specialization in APA. They were interviewed in three separate groups with at least one sports pedagogue and one physiotherapist in each group. The therapists had long experience of working with a goal setting approach among children with disabilities (they meet approximately 450 children with disabilities per year).

3.12.2 Data collection
The overall aim of this step was to identify potential problems that may arise when answering the BarnAs 1 regarding the questions and photos, and if relevant activities were included. The interviews were conducted in small groups of two or three therapists, with the interviewer, in a meeting room at BHC. The interviewer used prompt questions for the different activities in the BarnAs 1 including tell me what you think of these photos. In your experience, how does the child understand this question? What do you think are the challenges for the child when answering this question? Are there any questions that are difficult to separate? Do we ask questions about activities that we do not offer anymore? Are there any activities that are missing? The interviews lasted for approximately 30 minutes and were audio recorded.

3.12.3 Time frame
The interviews were conducted in December 2017 and January 2018.

3.12.4 Analysis
Thematic analysis with systematic text condensation (Malterud, 2012) was used, and included systematic text condensation, similar to the techniques used in the individual interviews with the CADs, and which are described in the next part of the chapter.
3.13 Individual interviews with CADs

3.13.1 Sample and participants
Purposeful sampling was used as a model for recruitment (Patton, 1990). The goal when recruiting using this method is to ensure that the material gathered has the potential to enlighten the question at hand. Internal validity is central, determining the kind of material that can form the best foundation for interpretations and findings that might divulge something new about the questions to be asked (Malterud, 2003).

Knowledge from the field is an important prerequisite in identifying the relevant sources from which to gather data. Several years’ of work experience at BHC, in various positions, informed selection of the interview candidates; and the multidisciplinary team, who knew patients well, also advised, to ensure representation from patients with various functioning levels, ages, sex, and who lived in different regions and surroundings.

Six CADs were interviewed. It is shown that, if the researcher has done solid, preparatory work, and has sound knowledge about the method, thorough knowledge of the field and a flexible strategy, data from a low number of participants (four to seven) can be sufficient to provide rich material (Hollnagel, Malterud, & Witt, 2000; Kuzel, 1999; Larsen, Oldeide, & Malterud, 1997; Malterud, 2003; Plas & Kvale, 1996). The quality of the selection of the participants is much more important than the number (Malterud, 2003).

The ages of the patients who were interviewed varied between 5 and 17 years, and both sexes participated. Both larger cities and rural areas were represented, as well as different regions in Norway. Two of the six respondents used wheelchairs on a permanent basis. The preparation for the interviews and the sampling were done through the first 2 steps of the project. The researcher gained a broad understanding of the field through the analysis of the answers from 2015 and through the interviews with the multi-disciplinary staff.
3.13.2 Data collection

The interviews were recorded onto a memory card in a mobile phone. This card was stored in the patient archive at BHC. After the interviews were transcribed, the transcriptions were stored in the same locked and fire-safe archive. The interviews were conducted in a meeting room at BHC. The CADs could choose if they wanted to come alone, together with a guardian, or with their contact person among the staff. One respondent came alone, two respondents came with their contact person and three respondents came with one of their guardians. The interviews lasted between 15 and 25 minutes. A full copy of the interview guide is provided in Appendix 5.

Some of the questions asked were:

Which activity have you liked the most to do here at BHC, what have been the most fun?

Is there anything you think has been less fun, anything you haven`t liked to do?

Can you say something about why it is like that? Why something is more fun to do than other things, and why you like something better than other things?

Do you get to influence on what you are doing here at BHC?

Are you a part of deciding what you are doing here? Do we listen to you when you are expressing your wishes? Are there room for you to make suggestions about what to do, and how to do it?

Is there something that is different here at BHC from home that makes you do or want to do other activities? If so, what might that be?

- With whom?

- Where you do it?

- When you do it?

Do you think that anything you are doing here at BHC is important for what you can do at home?
3.13.3 Analysis

Thematic analysis with systematic text condensation was used. This method, based on Giorgio’s phenomenological analysis (Giorgi, 1985), was later modified (Malterud, 1993). It has similarities with the procedure described in grounded theory (Strauss, 1990). The method is well suited for descriptive transverse analyses of phenomena that are described in data from many different informants for the development of new terms and descriptions (Malterud, 2003). The method consists of four steps (Malterud, 2003):

*Step 1 of the analysis*

The first is where the researcher forms an overall impression. All the transcriptions from the interviews are read. It is important not to place too much attention on the details at this stage; the purpose is to get the bigger picture. It is possible to take notes, but the material should not be systematized. When one has read through the complete material, it is time to summarize one’s impressions, and identify various themes that catch one’s attention. These are not results as such, but a first impression and a step towards organizing the data.

*Step 2 of the analysis*

In the second step, the researcher should identify the significant elements - transcribed text that say something about the themes from the first step (Malterud, 2003). By doing this identification, relevant parts of the data are organized. The researcher has to explore the text thoroughly and systematize it into code groups so that significant elements that speak to the same theme are arranged into the same code group. The code groups are then adjusted in relation to the themes in the first step. Some themes can be divided into several code groups, while others can be merged together, or perhaps their titles can be changed. It is important to be flexible in relation to changing the code groups (Malterud, 2003). A significant element may end up in several code groups, but if this happens often, it should be considered whether or not the codes are precise enough.
**Step 3 of the analysis**

The third step is referred to as condensation (Malterud, 2003). In this step, the codes are given meaning. Each code group is divided into subgroups based on which significant elements fit well together. Artificial quotations are extracted from the significant elements. A quotation may have content from several significant elements that are saying something about the same group. In this process, the researcher undertaking the analysis interprets the text, and the researcher’s education and work experience will influence how the artificial actual quotations are written. Each subgroup ends up with artificial text that is saying something about what the participants said towards or about the current theme.

**Step 4 of the analysis**

The fourth, and last, step is to summarize (Malterud, 2003). The parts of text are to be put together in a text that represents what the participants have said, and that gives insight to the current theme. Based on the artificial text, devised in Part three, an analytical text is constructed for each code group. The text should be able to say something about the part, or parts, of the research questions that the code groups are about. The summarized text represents the results of the assignment, and verbatim quotes from the participants can be included to give illustrations. At the end of the analysing process, it should be considered if the new text still is in context with the material from which it is gathered - the transcribed interviews. This is called re-contextualisation (Malterud, 2003), and the question should be asked: are the result describing what the participants meant during the interviews? The researcher should also consider if the findings are giving new information when compared to earlier research, and if there are any unexpected findings in the results.

**The use of artificial quotes in the third step**

There is some discussion among researchers about the use of artificial quotations in systematic text condensation. I have chosen to use them in order to follow Malterud’s method completely. To make sure that the artificial quotes and text represented the meaning of the CADs that I interviewed, I went back and read the
original transcripts an extra time, comparing the quotes to what the transcripts told me. I also used direct quotes from the interviews in the analysis. See Table 3.1 for examples of the process.
Table 3.1 Example of content analysis, step by step by the systematic text condensation

<table>
<thead>
<tr>
<th>Question</th>
<th>Verbatim text</th>
<th>Significant elements derived from the verbatim quotes</th>
<th>Artificial quotes based of the significant elements</th>
<th>Summary</th>
</tr>
</thead>
</table>
| **Why is it so that some activities are more fun to do than others are?** | P6: “Mmmh…Maybe because one does not master it so well.”  
P2: “P: I like better to do things that I am good at”  
P3: “P: It is about a persons interest” | Not mastering, like better-when good, about interest. | I like better to do activities that I am good at and interested in, than activities that I do not master. | The analysis shows a higher preferences for activities the CADs are interested in and that they prefer activities they can do over activities they do not master. |
| **When you look at these smileys, (showing a green positive smiley, a yellow neutral smiley and a red negative as shown in Figure 3.3), are they different in any way, what do you think?** | P3: This means that you don’t want to, maybe want to and really want to. (Pointing to one after the other.)  
P5: I think that that one is a smiley who is not very happy  
I: Mhm  
P: And that one is somewhat happy, and that one is very happy  
P6: Yes! Would very much like to, might want to, don’t want (Pointing to one after the other.) | Want to, don’t want to, really want to, not very happy, somewhat happy. Very happy, very much like to | This smiley is not very happy and means that I don’t want to, this is somewhat happy and means that I maybe want to and this is very happy and means that I would very much like to | The analysis show that the CADs understand how to use the smileys to express their preferences for the activity show in. |
3.14 Limitations

A limitation was that only six children with disabilities participated in the cognitive interviews. The small sample does not allow statistical generalisation of findings. However, a saturation was achieved in the answers. When performing qualitative interviews it is important to include informants who are talkative and have opinions to share. The ambition in this study was to include children with disabilities who were interested in sharing their experiences, and who represented different gender, age, functioning levels and were living in different geographical areas. The therapists at BHC, who knew the children, were helpful in finding suitable informants that fulfilled these criteria.

Another limitation is that all the participants included in the study were children with disabilities that have applied for a rehabilitation stay at BHC. This might mean that these children, or at least their parents, have an increased preference for physical activities, and might not be representative for all Norwegian children and adolescents with disabilities. However, the catchment area is large and the population is representative to the extent that it contains children/adolescents of different ages, gender, from different geographical areas with different functional levels/diagnoses, which generally match the Norwegian population of children and adolescents with disabilities.

To make an instrument that lets CADs’ own voices be heard, it would have been ideal to have the children make their own instrument, based entirely on the children’s perspectives. This is done to a certain point in the development of BarnAs 1 through basing the content on CADs’ own reported target activities and through the interviews with CADs. In the clinical testing of BarnAs 1 there was an opportunity for the CADs to add activities they missed, or to present other suggestions regarding the instrument.

A limitation to the interviews with the therapists was that the interviews were done in groups. This might have led to that some of the therapists being heard more than others. Individual interviews might have ensured that all respondents were heard on all questions. The main reason for still selecting to do group interviews was that this method had the potential to create interesting multidisciplinary-disciplinary...
discussions around the questions, and that this could trigger reflections among the participants, giving stronger answers to the questions that the interviews sought to enlighten.

It may also be a limitation that the part of the study used data that was gathered previously. This meant that there were no possibilities to change the questionnaire in any way during the data collection, and there was also no possibility to ask follow up questions.

3.15 Ethics approval and considerations

Ethics approval for this study was obtained from the Norwegian Regional Committee for Medical and Health Research Ethics (REC) reference number 2016/1469, see Åå 6, and by the Human Research Ethics Committee (HREC) at Charles Sturt University, reference number H17148.

The Norwegian Regional Committee for Medical and Health Research Ethics considered that the project would not present new knowledge about health and illness, and so the project falls outside of its mandate according to the Health Research Act, which presupposes that the purpose of the project is to gain new knowledge about health and illness (NOU, 2005, p 25). The ethics committee stated that because the data collection and the data collected were part of the routine admission to BHC, their approval was not necessary. Consequently, approval from REC was deemed not needed to complete the project. The HREC of CSU provided clearance based on the decision of the Norwegian REC.

The project was conducted in a secure way with regards to confidentiality and privacy. The answers from the participants in the retrospective study were contained in a secure database at BHC and were identified by ID numbers only to the researcher. Only the head physician at BHC had the ability to decode the ID numbers.

The interviews were recorded on a memory card in a mobile phone. This card was stored in the secured patient archive at BHC. After the interviews were transcribed,
the transcriptions were stored in the same locked and fire-safe archive. The information will be kept for one year and thereafter deleted. All the CADs and their guardians were provided with written and oral information about the study, and were asked to sign a consent form prior to participating in the interviews.
CHAPTER 4, RESULTS

4.1 Introduction

This chapter will describe the results of the three different parts of the study. It starts with the results from the retrospective study on the pilot version of BarnAs 1; then the results from the group interviews with the multi-disciplinary team at BHC will be presented, and lastly, the results from the individual interviews with the CADs on the revised version of BarnAs 1.

4.2 Retrospective study

The respondents in the retrospective study had a wide variety of different diagnoses, with cerebral palsy the most represented diagnosis with 126 cases. An overview of all participants’ diagnoses is shown in Table 4.1.

The tables on the following pages show the results of most popular activities overall (Table 4.2); least popular activities, top five activities ranked by the highest frequency of the response: “did not want to try the activity.” (Table 4.3); most popular activities in the age group 5-9 years, (Table 4.4); most popular activities in the age group 10-13 years, (Table 4.5); most popular activities in the age group 14-18 years, (Table 4.6); the five most popular activities among boys (Table 4.7), and the five most popular activities among girls (Table 4.8).
Table 4.1 Number of respondents in each diagnosis group n=341, for the respondents that answered the pilot version of *BarnAs 1* in 2015.
4.3 Most popular activities overall

In 15 out of 19 activities, 79% of the children answered that they maybe, or really, would like to try the activities in BarnAs 1, see Table 4.2. The five most popular/preferred activities overall were: Be in the pool, Ride/drive/tend to horses, Bicycle, Do outdoor activities and Individual sport/activity.

Table 4.2: Reported preferences for the 19 activities in the pilot version of BarnAS 1, all respondents n=314.

<table>
<thead>
<tr>
<th>RANK</th>
<th>Activity</th>
<th>Don’t want</th>
<th>Maybe want</th>
<th>Really want</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the pool</td>
<td>2.6%</td>
<td>11.4%</td>
<td>85.9%</td>
</tr>
<tr>
<td>2</td>
<td>Ride/drive, tend to horses?</td>
<td>12.3%</td>
<td>22.3%</td>
<td>65.4%</td>
</tr>
<tr>
<td>3</td>
<td>Play in the snow</td>
<td>18.2%</td>
<td>17.6%</td>
<td>64.2%</td>
</tr>
<tr>
<td>4</td>
<td>Bicycling</td>
<td>10.0%</td>
<td>28.2%</td>
<td>61.9%</td>
</tr>
<tr>
<td>5</td>
<td>Do outdoor activities</td>
<td>9.7%</td>
<td>31.0%</td>
<td>59.2%</td>
</tr>
<tr>
<td>6</td>
<td>Individual sport/activity</td>
<td>9.4%</td>
<td>31.7%</td>
<td>58.9%</td>
</tr>
<tr>
<td>7</td>
<td>Climbing</td>
<td>17.0%</td>
<td>29.0%</td>
<td>54.0%</td>
</tr>
<tr>
<td>8</td>
<td>Train in the gym</td>
<td>11.7%</td>
<td>34.6%</td>
<td>53.7%</td>
</tr>
<tr>
<td>9</td>
<td>Do water activities outdoors</td>
<td>20.8%</td>
<td>25.5%</td>
<td>53.7%</td>
</tr>
<tr>
<td>10</td>
<td>Alpine skiing</td>
<td>28.2%</td>
<td>20.2%</td>
<td>51.6%</td>
</tr>
<tr>
<td>11</td>
<td>Activities on ice/snow</td>
<td>24.6%</td>
<td>25.2%</td>
<td>50.1%</td>
</tr>
<tr>
<td>12</td>
<td>Going skiing/ski-pigging</td>
<td>26.7%</td>
<td>24.3%</td>
<td>49.0%</td>
</tr>
<tr>
<td>13</td>
<td>Move to music</td>
<td>25.8%</td>
<td>26.1%</td>
<td>48.1%</td>
</tr>
<tr>
<td>14</td>
<td>Activities on wheels</td>
<td>16.4%</td>
<td>36.4%</td>
<td>47.2%</td>
</tr>
<tr>
<td>15</td>
<td>Go/roll for a trip</td>
<td>19.9%</td>
<td>33.4%</td>
<td>46.4%</td>
</tr>
<tr>
<td>16</td>
<td>Team sports</td>
<td>24.9%</td>
<td>29.0%</td>
<td>46.0%</td>
</tr>
<tr>
<td>17</td>
<td>Play/play games outdoors</td>
<td>20.2%</td>
<td>39.3%</td>
<td>40.5%</td>
</tr>
<tr>
<td>18</td>
<td>Orienteering</td>
<td>28.2%</td>
<td>41.9%</td>
<td>29.9%</td>
</tr>
<tr>
<td>19</td>
<td>Practice wheelchair technique</td>
<td>65.7%</td>
<td>17.0%</td>
<td>17.3%</td>
</tr>
</tbody>
</table>
Table 4.3: Least popular activities, top 5 activities ranked by the highest frequency of the response: “did not want to try the activity.”

<table>
<thead>
<tr>
<th>RANK</th>
<th>ACTIVITY</th>
<th>DON’T WANT</th>
<th>DON’T WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Practice wheelchair technique</td>
<td>224</td>
<td>65.69%</td>
</tr>
<tr>
<td>2</td>
<td>Orienteer</td>
<td>96</td>
<td>28.15%</td>
</tr>
<tr>
<td>2</td>
<td>Alpine skiing</td>
<td>96</td>
<td>28.15%</td>
</tr>
<tr>
<td>4</td>
<td>Going skiing/ski-pigging</td>
<td>91</td>
<td>26.67%</td>
</tr>
<tr>
<td>5</td>
<td>Move to music</td>
<td>88</td>
<td>25.80%</td>
</tr>
</tbody>
</table>

Table 4.4: Most popular activities in the age group 5-9 years, n=127.

<table>
<thead>
<tr>
<th>RANK</th>
<th>ACTIVITY</th>
<th>DON’T WANT</th>
<th>MAYBE</th>
<th>REALLY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the pool</td>
<td>1.6%</td>
<td>10.2%</td>
<td>88.2%</td>
</tr>
<tr>
<td>2</td>
<td>Ride/drive tend to horses</td>
<td>5.5%</td>
<td>19.7%</td>
<td>74.8%</td>
</tr>
<tr>
<td>2</td>
<td>Play in the snow</td>
<td>11.0%</td>
<td>14.2%</td>
<td>74.8%</td>
</tr>
<tr>
<td>4</td>
<td>Bicycling</td>
<td>6.3%</td>
<td>24.4%</td>
<td>69.3%</td>
</tr>
<tr>
<td>5</td>
<td>Do outdoor activities?</td>
<td>6.3%</td>
<td>29.1%</td>
<td>64.6%</td>
</tr>
</tbody>
</table>

Table 4.5: Most popular activities in the age group 10-13 years, n=136.

<table>
<thead>
<tr>
<th>RANK</th>
<th>ACTIVITY</th>
<th>DON’T WANT</th>
<th>MAYBE</th>
<th>REALLY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the pool</td>
<td>3.7%</td>
<td>11.8%</td>
<td>84.6%</td>
</tr>
<tr>
<td>2</td>
<td>Individual sport/activity</td>
<td>5.1%</td>
<td>26.5%</td>
<td>68.4%</td>
</tr>
<tr>
<td>3</td>
<td>Ride/drive, tend to horses</td>
<td>14.0%</td>
<td>22.8%</td>
<td>63.2%</td>
</tr>
<tr>
<td>4</td>
<td>Play in the snow</td>
<td>24.3%</td>
<td>14.7%</td>
<td>61.0%</td>
</tr>
<tr>
<td>5</td>
<td>Bicycling</td>
<td>12.5%</td>
<td>28.7%</td>
<td>58.8%</td>
</tr>
<tr>
<td>5</td>
<td>Do outdoor activities</td>
<td>11.8%</td>
<td>29.4%</td>
<td>58.8%</td>
</tr>
</tbody>
</table>
Table 4.6: Most popular activities in the age group 14-18 years, n=78.

<table>
<thead>
<tr>
<th>RANK</th>
<th>ACTIVITY</th>
<th>DON’T WANT</th>
<th>MAYBE WANT</th>
<th>REALLY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the pool</td>
<td>2.6%</td>
<td>12.8%</td>
<td>84.6%</td>
</tr>
<tr>
<td>2</td>
<td>Do water activities outdoors</td>
<td>24.4%</td>
<td>16.7%</td>
<td>59.0%</td>
</tr>
<tr>
<td>3</td>
<td>Train in the gym</td>
<td>15.4%</td>
<td>26.9%</td>
<td>57.7%</td>
</tr>
<tr>
<td>3</td>
<td>Individual sport/activity</td>
<td>6.4%</td>
<td>35.9%</td>
<td>57.7%</td>
</tr>
<tr>
<td>5</td>
<td>Bicycling</td>
<td>11.5%</td>
<td>33.3%</td>
<td>55.1%</td>
</tr>
</tbody>
</table>

Table 4.7: The most popular activities among boys, n=196.

<table>
<thead>
<tr>
<th>RANK</th>
<th>ACTIVITY</th>
<th>DON’T WANT</th>
<th>MAYBE WANT</th>
<th>REALLY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the pool</td>
<td>2.0%</td>
<td>12.8%</td>
<td>85.2%</td>
</tr>
<tr>
<td>2</td>
<td>Bicycling</td>
<td>9.7%</td>
<td>20.4%</td>
<td>69.9%</td>
</tr>
<tr>
<td>3</td>
<td>Play in the snow</td>
<td>17.9%</td>
<td>16.3%</td>
<td>65.8%</td>
</tr>
<tr>
<td>3</td>
<td>Individual sport/activity</td>
<td>7.1%</td>
<td>27.0%</td>
<td>65.8%</td>
</tr>
<tr>
<td>5</td>
<td>Do outdoor activities</td>
<td>9.2%</td>
<td>28.6%</td>
<td>62.2%</td>
</tr>
</tbody>
</table>

Table 4.8: The most popular activities among girls, n=145.

<table>
<thead>
<tr>
<th>RANK</th>
<th>ACTIVITY</th>
<th>DON’T WANT</th>
<th>MAYBE WANT</th>
<th>REALLY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the pool</td>
<td>3.5%</td>
<td>9.7%</td>
<td>86.9%</td>
</tr>
<tr>
<td>2</td>
<td>Ride/drive tend to horses</td>
<td>5.5%</td>
<td>13.1%</td>
<td>81.4%</td>
</tr>
<tr>
<td>3</td>
<td>Do water activities outdoors</td>
<td>18.6%</td>
<td>19.3%</td>
<td>62.1%</td>
</tr>
<tr>
<td>4</td>
<td>Climbing</td>
<td>15.9%</td>
<td>24.1%</td>
<td>60.0%</td>
</tr>
<tr>
<td>5</td>
<td>Move to music</td>
<td>16.6%</td>
<td>26.9%</td>
<td>56.6%</td>
</tr>
</tbody>
</table>
4.4 Least popular activities

Two of the activities were the least popular, and these were *practice wheelchair technique, and orienteering*, with 224 respondents (66%) answering that they did not want to practice wheelchair technique, and 96 respondents (28%) did not want to try orienteering (Table 4.3). Based on these results, and considering that orienteering was no longer an activity offered at the BHC, these two activities were excluded from the revised version of the *BarnAs I*.

4.5 Variations among the different age groups

The analysis showed that there were only minor differences in preferences between the different age groups. Older children seemed to prefer doing more organized activities, whereas younger children seemed to prefer to participate more in unorganized activities. Being in the pool was the most popular activity in all age groups. The second most popular activity overall, ride/drive/tend to horses was not in the top five among the oldest age group. Bicycling and outdoor activities were among the top five in all age groups, (Tables 4.4, 4.5 and 4.6).

4.6 Variations among the different sexes

There were some minor variations between boys’ and girls’ preferences for activities, both groups ranked “to be in the pool,” as the most preferred activity, but in second place, the girls preferred the activity, “Ride/drive/tend to horses”, while the boys’ second most preferred activity was “ride a bicycle.” These two activities (ride horses and bicycle), were not among the top five in the opposite gender group, meaning that the most preferred activity among boys, were not among the five most popular activities among girls, and the most popular activity among girls, were not in the top five for boys, (Tables 4.7 and 4.8).
4.7 Analysis of the comments in the free text field

Of the 341 respondents, 133 left a comment in the free comments box at the end of the questionnaire. In reviewing the 113 free text comments, it appeared that the majority of the comments were about highlighting what activities the children would prefer to do during their stay at BHC. Comments like: “I am really looking forward to my stay” and “I really want to learn to ride” were common. A few children commented that they wished to try the winter activity of dog sledging (not included in the BarnAs 1) and play computer games. Using Virtual Reality (VR) and activity sensor based games was later added to the new version of BarnAs 1.

One parent commented that her/his child, who was 6 years old, needed support to answer the questionnaire. One child commented that he did not understand how to respond to the BarnAs 1. Finally, there were a few remarks regarding that it was strange that the BarnAs 1 contained seasonal activities that could not be done at the time of year that their stay was planned. There were two comments stating that it was a parent that had answered.

It is worth noting that no comments were made that the instrument was too long, and that only one out of 341 respondents commented that he did not understand how to answer. In addition, there were no comments about not understanding the smileys and only one comment about having to have help from an adult to answer, this was one of the respondents that also stated that it was a parent who had answered.

4.8 Group interviews with the multidisciplinary team at BHC

The result from the second step, the group interviews with therapists, showed that they considered BarnAs 1 to be easy to understand and answer by children. Both the interviews with the multi-disciplinary teams, and the individual interviews with the CADs were analysed by systematic text condensation (K. Malterud, 2012), a method that consists of four steps (Malterud, 2003); The method of systematic text condensation (K. Malterud, 2012) are described in detail in the previous chapter; 3 Methods.
4.9 Results

Important findings from the group interviews are described over the following pages with direct quotes from the transcriptions as examples. Three group interviews were conducted with therapists from the different teams working with children at BHC. The groups were named group 1, group 2 and group 3, for the purpose of the analysis. The respondents were three physiotherapists and five sports pedagogues. There were at least one sports pedagogue and one physiotherapist in each group. The physiotherapists were referred to as PH, and the sports pedagogues were referred to as SP. In group 1 and 3 where there were two sports pedagogues, they are referred to as SP 1 and SP 2. The group interviews with the therapists in the multi-disciplinary teams ended up with the two code groups: Consistency and understanding the smileys and relevant activities.

4.9.1 Consistency

PH, Group 2:
“We are pointing to a smiley to express what they want even before we have asked them to answer anything”

The answers from the pilot version of BarnAs 1, answered digitally prior to arrival at the Center, was brought to the goal setting meeting with the CADs, which happens at the first day of the stay in the institution, see Appendix 9. The therapists’ experienced that there was consistency between what the CADs had answered in the questionnaire about their preferences, and what they said about preferences in the goal setting meeting.

4.9.2 Understanding the smileys and relevant activities

SP 2, Group 1:
“The activities they say they really want to try are the same as the activities they have already answered with the green smiley to”

The multi-disciplinary team also said that many of the CADs talked about activities that they had seen in the questionnaire, and that they expressed preferences for the
same activities that were rated with a positive smiley when answering the questionnaire at home.

The respondents also meant that most of the activities seemed to be relevant for children with disabilities, except for orienteering, and that was no longer a prioritized activity at BHC and did not seem to be popular amongst children.

The therapists pointed out that the questions; “Play in the snow?”, “Try activities on ice/snow?”, “Going skiing/ski-pigging?”, and “Alpine skiing?” were difficult to separate for the CADs and that the questions asked about somewhat similar activities. Consequently, the question “Try activities on ice/snow” was dropped from the revised version.

SP 1, Group 2:

“Many of them are struggling to differentiate between the different winter activities. Not all understand the difference between alpine and cross country skiing, and very many are struggling with the question about activities on snow/ice, and what is different about that regarding to the other questions about winter activities”

Several respondents pointed out that ActiveYou 1 lacked a question regarding the use of Virtual Reality (VR) and movement sensor-based computer games, as these activities were popular among many children. One such question was added to the revised version; “If you had the opportunity, how much would you like to use video/VR games for training?”

PH, Group 3:

“VR games are really popular, especially among the children with low functioning levels”

The therapists agreed that the questionnaire was a valuable tool when it comes to goal setting for children with disabilities. An interesting point was that some of the therapists highlighted that BarnAs 1 also was a useful tool for talking about the activities the children with disabilities did not prefer to do. In the therapists’ experience, many children with disabilities say that they do not prefer the activity,
not because they do not want to do the activity, but because they believe that they are not able to do it, or master it. After discussions about how the activity can be adapted to suit the individual, the children often change their preferences for the activity.

In the group interviews with the multi-disciplinary teams, it also became clear that BarnAs 1 needed some changes in the design. It was emphasised that some of the photos were outdated, showing both old equipment and clothing, giving the impression that the questionnaire was not modern. The solution was to replace the photos with new, updated photos. Further, some of the children with disabilities did not seem to understand that it was possible to click through to see more options/photos of each activity. A technical change was made, so that the photos automatically rotated showing all different photos of each activity.

4.10 Results of the individual interviews with CADs

This section will provide the results from the individual interviews with six CADs related to the different themes the interviews explored. Examples of the transcriptions of the individual interviews are available in Appendix 4. The interview guide for these interviews are available as Appendix 5.

4.10.1 Overall impression and grouping of themes

All the interviews were read through to gain an overall impression, and to start the first sorting of the content. After reading the interviews, five theme groups were found. The headlines for the themes were selected based on the first impression gained from reading the transcripts from the interviews.

The themes ended up being:

1. **Doing activities at BHC and at home.** This theme was formed as many of the questions regarded doing activities, and because several respondents also talked about activities they did spontaneously

2. **Answering and understanding of the smileys.** This was one of the central themes the interviews sought to investigate.
3. **Understanding of various activities.** The understanding of the various activities in *BarnAs 1* was an important topic in the interviews, and was much discussed.

4. **Uncertainty and questions about pictures or activities.** This became a theme as it was evident that not all pictures were easy to understand among the respondents.

5. **Expressing own preferences, and deciding what to do.** This was also a central theme to investigate through the interviews. Several respondents also talked a lot about their preferences and were eager to point to the smileys during their interview.

Most text fell into Themes 2 and 3. The parts of the interviews that were not considered relevant at this time were left standing in the transcripts and not included in any theme group. This could, for example, be introductory talk about how their stay at BHC was going.

In the beginning, activities at BHC and activities at home were divided into two different code groups, but early on there was a need to merge these two into one, as many of the answers to questions about activities lead to the respondents spontaneously discussing activities both at home and at BHC.

4.10.2 **Significant elements, from themes to codes and the transition from theme groups to code groups**

Based on the theme groups and the information in each group, three headings were formed to represent the code groups. A code group can be defined as a group or collection of text from various interviews that spoke about similar topics in relation to the questions the project aims to clarify. The code groups, and their headings, were adjusted, as content from the theme groups was added to the suitable code group, ending in the following three headings:

*Participation in activities, Code group 1;* meant to describe activities in which the CADs participated independent of circumstances. This code group was mainly based on text from theme group 1; doing activities at BHC and at home.
Understanding of the instrument, Code group 2; which sought to describe their total understanding of the questions. This group consisted of both theme groups 3 and 4 which both had to do with the understanding of which activities that the instrument investigated.

How to answer the questions and making choices, Code group 3 to describe the CADs’ ability to choose and decide between the different questions in the questionnaire. This group generated the answers from themes 2 and 5, which were about how the respondents understood the smileys, and how they used them to express their preferences for the various activities.

Significant elements were moved from the theme groups to a suitable code group. Some significant elements were placed in two code groups. Some of the text from the theme groups were left out, as they were not relevant for any code group. There were significant elements from all interviews in every code group.

4.11 Results from the different code groups

4.11.1 Participation in activities
When asked what made some activities more fun to do than others, it was interesting to note that several children then talked about their activity competence or activity experience. It seems a sense of mastery or positive experience from an activity makes it more likely to be a preferred activity for the child.

Participant 2:
“\textit{I like better to do things that I am good at}”

Participant 5:
“\textit{I have tried that, so that was fun!” (Picture of canoeing)\textit{}}”

Other children emphasized the importance of having the right activity devices, suiting their disability in order to have a preference for an activity.
Participant 4:

“If I could sit in one of those” (A Joelette trekking cart in one of the photos from the question about hiking), I would very much like to try this”

The answer illustrates the importance that the photos show each activity performed in different ways, with and without activity devices.

4.11.2 Understanding of the instrument

Some of the activities were more difficult to understand from the photos, when not reading the text. Generally, 12 of the activities were well understood, but activities on wheels and dance/move to music were hard to understand.

Participant 1, when shown pictures of “ride/drive, tend to horses”;
I: What are these people doing?
P1: Ehm, yes here they are riding horses.
I: Mhm
P1: And riding horses and tidying up in the stable and brushing the horse

Participant 4, when show pictures of “climbing”;
I: Can you see what they are doing?
P4: Climbing
I: What would you have answered?
P4: I would have wanted to….it looks cool (pointing to the green smiley.)

Participant 1, when shown pictures of “try activities on wheels”;
I: Can you see what these people are doing?
P1: Ehm, I am not quite sure.
I: No...
I: Can you see that all of the things have wheels one them? That everybody is doing something on wheels?
P1: Mhm, ehhm, ...
Several children with disabilities had also difficulties with differentiating between questions about cross-country skiing and alpine skiing. The photos of these activities have to be changed and tested in a new group of CADs.

Participant 4, when asked about “cross-country skiing,” and “alpine skiing”;

I: Can you see what they are doing (showing alpine skiing)?
P4: They are skiing
I: Mhm, can you see what kind of skis, and if it is alpine or cross-country?....
P4: Not cross-country
I: No, very good, what would you have answered if we asked you if you wanted to do that?
P4: Maybe (pointing to the yellow smiley)
I: Maybe, then we will put that one away, can you see what they are doing here (Showing cross-country skiing)?
P4: Skiing
I: Mhm, is it the same type of skiing or is it different?
P4: Hmmm, maybe the skis are a bit longer.

4.11.3 How to answer the questions and making choices

All six participants clearly understood the meaning of the smileys and how to use them to express their preferences. They understood that the red smiley meant that I do not want to try, the yellow one meant that I maybe want and the green one meant that I really want to try the activity shown at the photo. This can be illustrated by the following quote from one of the interviews:

Interviewer: “What do you think when you see these pictures of smileys? Are they different in any way, do you think anything different between the green, the yellow and the red one?

Participant 3: “This means that you don’t want, want a bit and really want.” (Pointing to the different smileys as he explains).

Participant 3 when answering to specific activities;
“Hiking, and I love it very much, so green!”
“Riding horses, green, that is very funny”

Participant 5: I think that that one is a smiley who is not very happy (pointing to the red smiley)  
I: Mhm  
P5: And that one is somewhat happy (pointing to the yellow), and that one is very happy (pointing to the green smiley.)  
Participant 6: Yes! Would very much like to, might want to, do not want (Pointing to one after the other.)

4.12 Summary of results

The aim was to develop, validate and implement a new web-based measure of children’s preferences for physical activities, BarnAs 1.  
The retrospectives study consisted of 341 children (79%) that responded to the web-based BarnAs 1 (145 girls and 196 boys between 5 and 18 years (mean age 11 years), with cerebral palsy being the most common diagnosis.

The result showed that in 15 out of 19 activities, 79% of the children answered that they maybe or really would like to try the activity (Table 4). The five most popular activities were: Be in the pool, Ride/drive/tend to horses, Bicycling, Do outdoor activities and Individual sports/activities. The result was consistent with the previous results regarding the children’s identified COPM goals (first step) and the therapists' experiences from the goal setting process with the children at BHC. The result was consistent with the previous results regarding the children’s identified COPM goals (A. Nyquist, 2012) and the therapists' experiences from the goal setting process with the children at BHC. The retrospective study also showed that there were very few comments about how to answer the questionnaire, indicating that it is user-friendly and easy to understand.

Two of the activities were distinguished to be the least popular, and these were Practice wheelchair technique and Orienteering. Here 224 respondents (66%)
answered that they did not want to practice wheelchair technique, and 96 respondents (28%) did not want to try orienteering. Based on these results, and considering that orienteering was no longer an activity offered at the BHC, these two activities were excluded from the revised version of the instrument.

The result showed only minor differences in preferences between the different age groups. Older children preferred to do more organized activities, whereas younger children preferred to participate in less structured activities. Being in the pool was the most popular activity, and bicycling and outdoor activities were among the top five in all age groups.

There were some minor variations between boys’ and girls’ preferences for activities. Both groups ranked being in the pool as the most preferred activity, but in second place, the girls preferred the activity, horseback riding, while the boys’ second most preferred activity was bicycling.

The result showed the 19 items in the ActiveYou1 had acceptable internal consistency, with a Cronbach’s alpha coefficient of 0.77. (Tavakol & Dennick, 2011)

The interviews with the multidisciplinary teams at BHC confirmed that the questionnaire was easy to understand, and easy to answer. It was also consistent with what the CADs had answered prior to arrival, and what they said in the goal setting meeting when they arrived at the institution. Two activities were removed after these interviews, as they were deemed not relevant from the therapists’ experience. Another question was also removed, as it was too similar to other questions. One question was added, as it was a relevant activity about which CADs had asked.

The team members thought that ActiveYou1 was a valuable tool in the goal setting process. An interesting point was that some of therapists highlighted that ActiveYou1 also was useful for talking about the activities the children did not prefer to do. The children sometimes claimed that they did not prefer an activity, not because they did not want to do it, but because they believed they were not able to do it. After discussions about how to adapt the activity to suit the individuals, the children often
changed their preferences for the activity. The children realized that it was possible for them to do something they first thought was impossible.

The last step was the individual interviews with CADs who attended (re)habilitation stays at BHC in June 2018. These interviews investigated the applicability of the revised version of the instrument. It showed that the smileys were well understood and that the CADs used them spontaneously to express their preferences. It also showed that the relevant activities were included. Most pictures were well understood, but the interviews also showed the need to change the pictures for four of the activities. The revised version of the instrument is available as Appendix 8.

The next chapter will discuss the results found in the different parts of the study. It will also discuss how these results might impact both CADs, service providers in re/habilitation and the society.
CHAPTER 5, DISCUSSION

5.1 Introduction

This shows the implications of this study, both for the patients, rehabilitation institutions and for health and social service providers. It describes the importance preferences have on participation by CADs, and the importance of having a self-reported instrument for mapping preferences. It will also discuss why some activities were dropped from the pilot version of *BarnAs 1*.

The overarching aim of this study was to gain knowledge about how service providers can optimize CADs’ participation in physical activities by developing and applying tools for identifying children's own preferences. User participation is a central aspect of modern health and social services, but it can be challenging to find effective ways to implement it in daily clinical practice, especially for groups like CADs.

This study developed, validated and implemented a new web-based measure of CADs’ preferences for physical activities, *BarnAS 1*. Emphasis was laid on developing an instrument that was user-friendly enough for CADs to respond themselves with little or no help from guardians or other adults.

5.2 Preferences and their importance in relation to participation

A main goal for health, social and pedagogical service providers in the field of rehabilitation is to optimize participation in different life arenas for children and adolescents with disabilities. It has been concluded that preferences are the most important predictors of participation in children with disabilities (Shields et al., 2015). Preferences have also been identified to be important mediators for a person’s participation level (Shields et al., 2015). Children’s past experience of enjoyment when doing an activity will influence future preferences for the activity (Imms et al., 2017). The preferences may also be influenced by the child’s possibilities, such as accessibility of activities and the child’s activity competences (Elster, 1989 in Skille, 2011; Bult et al., 2014).
Consequently, it is important to seek activities that match the overall preferences and competencies of the child. This can be illustrated with these quotes from one of the individual interviews with the CAD.

**Interviewer:** *Eh, why is it so that some activities are more fun to do than others are?*

**Participant 1:** *Mmmh...Maybe because one does not master it so well.*

**Interviewer:** *Mhm, that it is funnier to do what one masters?*

**Participant 1:** *Nods*

### 5.3 Participation among CADs

One can assume that children with disabilities experience less success in physical activities, and there is evidence to show that children with disabilities encounter restrictions to participation in various activities due to physical, social, and attitudinal barriers (Bult et al., 2011; King et al., 2007). These studies have shown that children with disabilities participate less in physical and skill-based activities than able-bodied children. Further, children with disabilities often do not participate in activities they prefer, especially children with severe disabilities who find a higher proportion of activities in which they do not participate, but would like to (Law & King, 2000). Mapping the preferences of CAD’s is important for rehabilitation service providers in order to direct the effort to the activities that they really want to participate in themselves. It is also important to show them the possibilities to participate in activities by using activity aids, they ight understand that it is possible for them to do an activity they thought was impossible for someone with their functioning level. Rehabilitations stays, where CAD’s can learn activities that they prefer, in a safe and accepting environment, with eventually needed activity aids are effective to enhance participation for this group.

### 5.4 Considerations when excluding activities from the final version

Based on the importance of finding preferred activities to enhance participation it was essential to include relevant and preferred physical activities that were accessible at BHC and in the local environment. The search for relevant activities was done by
looking at the answers and the free text comments from the pilot version of BarnAs 1, through groups interviews with the multidisciplinary teams at BHC and through individual interviews with CADs. The activities in the pilot version BarnAs 1 were deemed to be relevant with three exceptions.

The activity “practice wheelchair technique” was the most non-preferred activity by far. This was the only activity including the word practice and perhaps children did not experience the activity as enjoyable. “Practice wheelchair technique” might be perceived more as a means of doing an activity, such as wheelchair basket, than a fun activity per se. This activity was therefore excluded from the final version.

Orienteering was the other activity that many children did not prefer to try, or answered that they only maybe wanted to try. To do the activity certain activity competences are required, such as mobility and visuospatial skills. Maybe orienteering was found to be too hard/difficult to perform for the children, since all the children had disabilities and many of them motor impairments. The multidisciplinary team also described orienteering as a dated activity which was not offered on a regular basis. This activity was also excluded from the final version.

The pilot version also consisted of four different questions about various activities on snow and/or ice. These were: play in the snow; go skiing/ski-pigging; go alpine skiing and try activities on snow/ice. The therapists had a clear understanding that these questions were too similar and that the CADs had a hard time differentiating between them. As a result; try activities on ice/snow was dropped from the final version.

5.5 Factors that influenced the preferences for various activities for CADs

The results from the individual interviews with children indicated that the children’s sense of mastery influenced their preferences for activities. In the group interviews with therapists it was pointed out that the children sometimes claimed that they did not want to try the activity, since they thought it would be too hard for them. Studies by (Engle-Yeger & Kasis 2012; Bult et al., 2014) have illustrated that children with lower level of self-efficacy also had lower preferences for activities and children with disabilities have lower preferences for leisure activities compared to children without disabilities. Therefore, asking children which activity they would like to try,
and discuss what potential barriers they may encounter to participate, is important, so that the children with disabilities do not “settle for less”, estimating that activities are too difficult for them (Bult et al., 2014).

5.6 Making the instrument user friendly for CAD’s

An important dimension in the validation process was to investigate if the instrument is easy to use, to understand and to answer, regarding photos, texts and smileys. The importance of making the instrument user friendly enough for CAD’s to answer themselves was the main reason that interviews was chosen as the method to further develop and validate the instrument. Otherwise it would have been relevant to use, for example the Content validity index (Polit, Beck, & Owen, 2007). Great emphasis was placed on finding photos that could neutrally illustrate different activities. Children with different gender and ages were featured on the photos. The reason for this was to increase understanding of the activity and not to portray certain activities as girl-respectively-boy activities, or intended for specific ages. It was also essential that the children could see that the activity was possible to do both with and without assistive devices, since all children regardless of disability should be able to participate in the activity. The importance of this can be illustrated with these quotes from the individual interviews with the CADs, this participant used a wheelchair.

Interviewer: *Then there is this one (Finding pictures of; go skiing/ki-pigging.)*
Participant 2: *Here they are walking on skis (Pointing to one picture of people walking on skis.)*
Interviewer: *Yes*
Participant 2: *Here they are pigging (Pointing to another picture of a person pigging sitting in a ski cart.)*
Interviewer: *Yes*
Participant 2: *I would very much like to do that*
Interviewer: *That's good*
Participant 2: *It is pigging for me, that I want to do*
Furthermore, it was important that understanding and estimation of preferences were simple. Therefore, only three different options of smileys were used. Drawing face scales, similar to smileys, have proven to be useful for young children’s estimations, especially of pain (Carl, 2006). The lack of ethnic or gender features make them applicable to a broad demographic group of children.

In the development of BarnAs 1, it would have been ideal to have the children make their own instrument, based entirely on their own perspective to optimize user involvement. This could only be partly achieved by basing the content of BarnAs 1 on children’s own reported and preferred goal activities and by individual interviews with children. In the clinical testing of BarnAs 1 there was also an opportunity for the children to add activities they missed or to present other suggestions regarding the instrument.

5.7 The importance of a self-reported instrument

As the BarnAs 1 is meant to explore preferences for physical activities in children and adolescents with disabilities, it is essential that the children can answer the instrument themselves. There are an increasing number of participation questionnaires for children, but the majority are proxy-rated versions (Adair et al., 2018). The preference for activities is, like participation, a personal subjective experience, and therefore may be difficult to capture by someone else. Therefore, it was important that BarnAs 1 was child-friendly, easy to understand and to answer. This was investigated mainly through individual interviews with children.

The use of both quantitative and qualitative methodology in this study, is a strength of the study, and the best way to answer these complex research questions. The quantitative results give an overview of the preferences of children with a range of disabilities during stays at BHC, and the qualitative results give deeper insight in the children’s preferences on an individual level (Malterud, 2003).

There are many different intrinsic and extrinsic factors that affect the children’s preferences for activities, such as experiences, skill competence, self-efficacy,
environment and people. In order to gain a deeper understanding of an individual’s preferences, one must also take into account and investigate various influencing factors.

5.8 Individual consequences

There is a correlation between a person’s self-efficacy and preferences, and children with lower levels of self-efficacy demonstrate fewer preferences for activities (Engel-Yeger et al., 2012). The child’s self-efficacy is influenced by previous experiences of success. This shows the importance of giving these children and adolescents positive experiences with activities. To do so, the activity, and not the person, have to be adapted. This can be done, both by activity aids or by carrying out the activity in an alternative way. It is also important that it is an activity that the child wants to do, and have chosen. This will increase the internal motivation to master the activity.

Preferences for activities are based on the child’s interests, and will influence the child’s level of participation. This highlights the importance of considering children’s activity preferences when planning an intervention. Consequently, it is essential to use valid and reliable instruments to capture the child’s preferences, and it is desirable that, if possible, the child him/herself answers questions about his or her preferences. This instrument, BarnAs 1, will be a helpful tool in enhancing participation among CADs as it gives them the opportunity to express their preferences to the habilitation and rehabilitation institution that helps them. This, again, will lead to better self-efficacy and higher participation in preferred activities among CADs. Higher participation among this group will be beneficial both for the individuals, for their families and for the communities in which they live. Higher self esteem among the CADs will lead to higher participation both in school and in leisure time activities, which will make them more independent and more likely to master other areas of life. This study shows that it is common to like better activities that one masters, therefore it is important to gain the skills to master the activities that one prefers, and that this will give a boost to the individuals self-confidence.
5.9 BarnAs 1 -impact on daily services

It is clear that the implementation of BarnAs 1 has had an effect on the daily routines, and how the multidisciplinary team works, at BHC. When preferences are mapped before the CADs attendance at the centre, they also come with an expectation that the stay, to some extent, is adapted to their preferences. Their answers to BarnAs 1 are central in the first meeting they have with their contact person at BHC, and BHC staff use the CADs answers when they are making the CADs schedules for the stay.

One of the interesting findings from the use of BarnAs 1 was that the multidisciplinary team reported that the instrument was a useful tool for talking about the activities that the CADs reported that they did not want to do. Often they answer that they did not want to do it for the obvious reason that they really did not want to, but there were also many cases where there were other reasons. Examples of these included that they did not know how to do a particular activity, and thought it was embarrassing to do it because they thought they were bad at it or did not know that it was possible for them to do the activity. In several cases, it led to an activity that they had answered that they did not want to do, became be a favourite activity when they had the possibility to learn the activity in safe and adapted surroundings at a BHC.

Another interesting finding is how positive the target group is towards various activities. The answers clearly show that except for two activities, orienteering and practice wheelchair technique, most respondents answered that they would really like to try the activity. This has also been shown in otherwise for children in the autism spectre (Adcock & Remus, 2006) and among people with disabilities in various age groups (Kosma, Maria, Bradley, Cardinal & Rintala, 2002).

5.10 Implications for practice and future use

An important step for the habilitation and rehabilitation services from this study would be to structure and formalize CADs influence on the various services they meet during their life. For institutions like BHC and others, this knowledge will be useful in order to adapt services in a way that gives the patients better outcomes of
their rehabilitation stays. It is found that service delivery is ideal when it is goal-oriented, family-centred, collaborative, strengths-based, ecological and self-determined (An & Palisano, 2014). Randomized controlled studies (Novak, Cusick, & Lannin, 2009; Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Salem & Godwin, 2009; Van Den Broeck et al., 2010), show that a goal-directed approach of practice of real tasks in real or natural environments are both more effective than no therapy, and more effective than general therapies which focus on impairments of movement and muscle performance.

This study will result in an instrument that makes it possible for services providers to set goals together with the CADs that is based on the CADs` own preferences, making the goals more likely to be followed up and met by the CADs.

At present, the main tool in use at BHC is the APA (Adapted Physical Activity), and in this discipline it especially important to see the pedagogical and usable potential of this knowledge. Including CADs own voices in different phases of the rehabilitation process could be a good step forward in developing a culture for real user influence in the field. *BarnAs 1* has proven to be effective in allowing CADs to have a say about their programs at BHC.

The results of this project will give service providers and researchers at BHC, and nationwide, an increased understanding of important factors influencing successful goal attainment related to physical activity in children and adolescents with disabilities. Knowledge of essential elements for goal attainment will facilitate the design of intervention models in further research. *BarnAs 1* can be used as a framework where the activities included can be interchanged to suit various environments and settings. *BarnAs 1* will be applicable and efficient to be used in a variation of habilitation units and in community settings. It is also possible that this instrument can be used internationally as while the framework is consistent, the questions and answer alternatives can be changed to suit different surrounding and contexts.

The use of both quantitative and qualitative methodology, with respondent triangulation, is considered to be a strength of the study, and the best way to answer
these complex research questions. The quantitative results give an overview of the preferences of children with a range of disabilities attending stays at BHC, and the qualitative results give deeper insight in the children’s preferences on an individual level. (Kirsti Malterud, 2003). A limitation was that only six children with disabilities participated in the cognitive interviews. It might be useful to test the instrument among a larger group of respondents. Another limitation was that all the participants included in the study were children with disabilities who had applied for a rehabilitation stay at BHC. This might have given a selection bias regarding increased preference for physical activities, and might not be representative for all Norwegian children and adolescents with disabilities. However, the catchment area was large and the population was representative to the extent that it contained children/adolescents of different ages, gender, from different geographical areas with different functional levels/diagnoses, which generally match the Norwegian population of children with disabilities.

CHAPTER 6, CONCLUSION

This study was conducted at BHC with CADs who were coming to, or were already attending the institution for a rehabilitation stay. Multi-disciplinary teams, consisting of physiotherapists and sports pedagogues at BHC were also included and interviewed. This study consists of three parts.

The first part consisted of a retrospective study of the answers given by 341 CADs in 2015 on a pilot version of the instrument.

The second part included group interviews with the multi-disciplinary teams to examine their experience with the use of the instrument.

The third part consisted of individual interviews with CADs based on the revised version of BarnAs I. These interviews were undertaken in the summer of 2018 with six CADs who attended a rehabilitation stay at the institution.
The study has shown that BarnAs 1 is a valid instrument for mapping activity preferences in children and adolescents with disabilities. It also shows that BarnAs 1 contains relevant physical activities for the target group. The need for such an instrument comes from the clinical practice at BHC.

User participation is becoming more and more important in the habilitation and rehabilitation services. In Norway, the current health minister, Bent Høie, is using the term: “the patients’ heath care system,” (Hoie, B 2014, July 01 Pasientens helsetjeneste. Retrieved from https://www.regjeringen.no) meaning that it is the patient that should make the choices for his or her treatment. This instrument will be a good tool for improving children’s and adolescents’ user participation in habilitation and rehabilitation services.

It was an important goal of this project that we wanted to hear the children’s own opinions, not the opinions of their parents, guardians or other adult helpers. To achieve this, great emphasis was laid on making the instrument easy to understand and easy to answer. This was given more importance than having very detailed and specific options for answering. The instrument also had to show the children their possibilities. Not all children who use wheelchairs know that there are, for example, adapted bikes for them, and that it is possible for them to bicycle. To show the possibilities for people with various disabilities we carefully took and selected pictures that showed activities done in different ways, with and without various activity aids. It was also important that photos were found that could neutrally illustrate different activities, and photos that showed children and adolescents of different ages and genders.

The instrument is answered by clicking one of three different smileys; this was chosen to make it easy for the children to state their preferences. This study shows that this way of answering is well understood among the target group and that they understand how to use these smileys to express their preferences for the shown activities.
The multidisciplinary team that tested the instrument is clear that the questionnaire is a valuable tool when it comes to goal setting for children with disabilities in a habilitation and rehabilitation setting, both for talking about activities they prefer and for talking about activities they do not prefer, and why they chose as they do.

*BarnAs 1* is now in use at BHC were all CADs between 5-18 years are sent the questionnaire about three weeks before they arrive for their rehabilitation stay. Approximately 420 CADs each year, with a wide variety of diagnoses, come from across Norway. Two other rehabilitation institutions, Red Cross Haugland Rehabilitation Center and Valnesfjord Healthsports Center also started to use *BarnAs 1* in the autumn of 2018, and are reporting that it is a useful tool that they will continue to use on a regular basis.

*The BarnAs 1* will contribute to evidence based (re)habilitation services and hopefully enhance participation in our target groups. The instrument is already in use in other (re)habilitation institutions in Norway

**6.1 Recommendations**

The aim of this study was to further develop, validate and implement a new web-based measure of children’s preferences for physical activities, *BarnAs 1*. The study also tested the instrument’s content validity and feasibility. As these aims were met, the following recommendations are based on these aims

1. *BarnAs 1* should be used in habilitation and rehabilitation for CADs to ensure that the CADs own opinions are heard when planning the services, and through this real user participation will be achieved as it is a reliable and valid instrument for mapping CADs preferences.
2. It is important to explore CADs reasons for the preferences they express. Are their choices based on what they really want or not, or are their choices limited by impressions that various activities might be too difficult or not suitable for them?
3. It is important to show CADs their possibilities to undertake various activities in their own way. A good way to do this is by showing them pictures of CADs doing the activities, both with and without activity aids, to give them the understanding that the activity is possible for CADs with various functioning levels.

4. It is important that preferences are mapped in advance, as this will lead to a more effective a better and more effective goal setting process for the service providers in a rehabilitation setting for CADs.

Mapping preferences is essential in a rehabilitation setting for children and adolescents with disabilities. Participation for activities for this group is driven by their own preferences for various activities, and is the most important mediator for participation. BarnAs 1 is a valuable tool that contributes to enhancement of participation in physical activities among CADs. The results of this project have been submitted as an abstract to the European Academy of Childhood Disability (EACD) 2019 in Paris and has been accepted as an oral presentation, see Appendix 3.


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Appendix 1 Pictures from the daily life at BHC

The reception area in winter time

The surroundings, the Center in the bottom left
Climbing indoors

Bicycling
Group activity indoors
Appendix 2 Submitted abstract to European Academy of Childhood Disability 2017 Conference and acceptance letter for presentation

Instruments for mapping activity preferences for children and adolescents (5-18) with disabilities: A review of the literature

Introduction:
A main goal for health, social and pedagogical service providers is to optimize participation at different life arenas for children and adolescents with disabilities (CAD). Involvement in physical leisure activities gives children and youth in general a sense of belonging, opportunities to fulfill personal goals, and to develop and grow as individuals. (Skille & Østerås, 2011)
Participation based on the individual’s preferences promotes both learning, knowledge of self and a sense of mastery.

BarnAs 1 is a Norwegian assessment tools under development, which aims to assess preferences of activities among CAD.

Methods:
A literature search has been done in order to find other valid instruments available for measuring CAD’s preferences for activities.

Results:
5 instruments were found that partly mapped self-reported activity preferences among CAD, while one meet all criteria’s.

Conclusion
The preferences for activities of children (PAC) is used to assess children’s self-reported preferences for recreational, active physical, social, skill-based and self-improvement activities. It shows satisfactory results for clinical use of the Norwegian version (H. L. Nordtorp, A. Nyquist, R. Jahnsen, T. Moser, & L. I. Strand, 2013). However, because of restrictions put in place by the publisher, the Norwegian version could not be widely disseminated. The scaling of the original version has also proven to be too difficult for children to understand without substantial help and guidance. The instrument is about 15 years old, and not up to date with many of current activities CAD participate in. Therefore, there is a need for another updated and validated Norwegian instrument to evaluate preferences for participation in activities in CAD.
Acceptance letter for poster presentation at the EACD 2017

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Conference : Annual Meeting of the European Academy of Childhood Disability 2017
Abstractnr. : 376
Title : Instruments for mapping activity preferences for children and adolescents with disabilities: A review of the literature
Dear Mr Dalen,
Thank you for submitting an abstract for the 29th annual meeting of the European Academy of Childhood Disability (EACD), Steps into the future, to be held May 17 - 20, 2017, in Amsterdam, The Netherlands.
On behalf of the scientific committee we are pleased to inform you that the above mentioned abstract has been accepted for POSTER PRESENTATION.
POSTER INFORMATION
The sizes of the poster boards are 147cm (height) x 97cm (width) – portrait format. Poster fixing material will be provided at the registration desk.
PROGRAM
The final program will be available on the 29th EACD conference website in March 2017. We will inform you by e-mail about the exact date, time and instructions for your presentation as soon as the conference program is final.
REGISTRATION
All presenting authors of accepted abstracts must register online for the conference before the deadline of the early registration fee March 1, 2017. Presenting authors not registered by this date will not be included in the final program and will not have their abstract(s) published in the conference abstract book. If you will not present your abstract yourself, but a co-author will do this instead, please inform us.
In case you are not registered yet, please visit the website: www.eacd2017.org/registration.
ACCOMMODATION
If you look for accommodation in Amsterdam you can book early at www.eacd2017.org/registration/accomodations.
CONFERENCE WEBSITE
For more information we would like to refer you to the conference website as this will be updated regularly www.eacd2017.org.
We look forward to meeting you in Amsterdam!
With kind regards,
On behalf of the scientific committee of the 29th EACD conference
Annemieke Buizer and Annet Dallmeijer, co-chairs scientific committee
Jules Becher, President
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Appendix 3 Submitted abstract to European Academy of Childhood Disability 2019 Conference and acceptance letter for presentation

Content validity and feasibility of ActiveYou 1 – a new web-based instrument for mapping activity preferences in children and adolescents with disabilities

Introduction
A main goal for health and service providers is to optimize participation for children with disabilities. Children’s preferences seem to be one of the most important predictors of participation. Currently no web-based measure of children’s preferences exists.

Patients and methods
Content validity and feasibility of a new web-based measure of children’s preferences for physical activities are investigated. The instrument was developed in several steps. A review of 149 children with disabilities’ preferred goal activities was performed to identify relevant activities to be included. A pilot version of ActiveYou-1 was sent to 341 children with disabilities who participated in a rehabilitation stay at the Beitostolen Healthsports Centre (BHC) in Norway. Semi-structured group interviews were conducted with therapists working at BHC to identify potential problems that may arise when answering ActiveYou-1. Finally, qualitative interviews were conducted with six children with disabilities in order to validate the new version of ActiveYou-1.

Results
Based on the analysis of the 149 children’s preferred goal activities, 19 physical activities were identified to be included. The results from the pilot trial, resulted in three activities being changed; orienteering, practice wheelchair technique were excluded, a new sorting of activities on snow was done, play computer games/virtual reality was added. The interviews with therapists and children with disabilities showed that ActiveYou-1 included relevant physical activities and was easy to understand and answer in a web-based version.

Conclusion
ActiveYou-1 proves to be a valid and feasible, web-based instruments for mapping activity preferences in children and adolescents with disabilities.
Acceptance letter for an oral presentation at the EACD 2019

Dear Mr Dalen,

We are glad to inform you that your communication "Content validity and feasibility of ActiveYou 1 - a new web-based instrument for mapping activity preferences in children and adolescents with disabilities" (ref.8028) has been selected to be presented as a Oral presentation during the EACD Conference.

The conference will take place at the conference centre of la Cité des Sciences et de l'Industrie (City of Sciences and Industry) of La Villette in Paris, from May 23 to 25.
More information on: www.eacd2019.org

We will come back to you soon for practical information.

In order to confirm your participation, please register to the conference before the 15th of February.
You will benefit from the early bird rate if you register before the 31st of January.

We are looking forward to welcome you in May in Paris

Yours faithfully,

Christopher Newman, Chair of the scientific committee
Sylvain Brochard, President of the conference

Appendix 4 Transcripts 1 and 2 from the individual interviews with CADs

Transcription Interview 1.
I: Hello, and welcome, have you just been training?
P: Yes.
I: My name is Lars Kristian, and I work a lot with planning what you are going to do when you are here at BHC, so what I want to ask you today is which activities you like to do?... And I want to ask you, I don’t remember that before you came here, you answered a survey on the internet with smileys?
P: Mhm
I: And then I would like to show you some pictures to find out if the activities we are asking you about are the one that you do or don’t want to do.....I will be recording what we are talking about on my telephone, that is to remember correctly what we talked about,
P: Mhm
I: And if you want to quit the interview at any time, and don’t want to participate anymore, you can just tell me at any time, and you and (B) leave.
P: Mhm
I: Eh, I am not going to write your name on any of the answers you give, so no one can find out what which of you children answered, so you are free to answer absolutely what you want. No answer is wrong or correct......Great.
I: What have you liked most to do, while you have been here at BHC?
P: Eeehm, to be in a canoe.
I: Oh yes @, that's good
I: Ehhm, is there anything that has not been fun?
P: ...No
I Everything has been at least a little funny?
P: Nods
I: Yes, great.
I: Eh, why is it so that some activities are more fun to do than others are?
P: Mmmh...Maybe because one does not master it so well.
I: Mhm that it is funnier to do what one masters?
P: Nods
I: Mhm
I: Is is somethings you do here at BHC that you don’t do at home, something that is easier to do here?
P: Eh..yes.
I: Mhm.
I: Do you get to take part in the decisions about what you are going to do while you are here?
P: Yes
I: Yes, do they listen to you if you suggest anything, and do you get a say in what you want to do and such?
P: Yes, nods.
I: Great
I: Do you think that you will continue to do anything of what you have learned here when you come home?
P: Yes..
I: Yes, that is great
I: What to do think about when you see these smileys?
P: I think that that one is a smiley who is not very happy
I: Mhm
P: And that one is somewhat happy, and that one is very happy
I: So good, not at last we are going to look at people who do different activities.
P: Mhm
I: And I want to hear with you if it is easy to see what they are doing in the pictures, and if you would have liked to do them. ...
I: What are these people doing?
P: Ehhhh, yes here they are throwing ball or ..... I do not quite know.
I: No? Where are they?
P: At BHC
I: Yes, are they outside or are they inside?
P: They are in the pool.
I: Mhm
I: If we had asked you to show by smileys if you wanted to do this, what would your answer be?
P: I didn’t quite understand what this was? (points to one of the pictures)
I: No, I agree with you, it was a bit hard to see what they were doing. Maybe we should use another picture of somebody swimming and it might be easier to understand what they were doing?
P: Yes, nods.
I: Mhm
P: For example that one? (points to another picture)
I: Mhm
P: Here you can much easier see that this is a person swimming through a ring
I: Right, that was a very good tip; would you have pressed the green, yellow or read on that?
P: I would have pressed green!
I: Oh, so you like the pool?
P: Nods
I: Great
I: Then over to the next pictures...
I: What are these people doing?
P: Eh, yes here they are riding horses.
I: Mhm
P: And riding horses and tiding up in the stable and brushes the horse
I: Mhm
P: Here I would have chosen this one (points to a picture)
I: Yes, there it was easiest to see
P: Yes, there it was easiest to see what they were doing
I: Right
P: Because, if you look at that picture, people will think that they only are going to groom a horse. (points to another picture)
I: Yes, yes… There are some that think that it is scary to ride, and that only wants to stay and groom the horses instead
B: Mhm
P: Yes
I: What would you press on this one, of the smileys?
P: Mm, I would press this one
I: You don’t want to ride?
P: No
I: Then we would answer exactly the same, I don’t want to ride horses either
B: Me neither @

I: What are these people doing?
P: Yes, they are cycling.
I: Mhm......
P: I would have chosen this one (points to one of the pictures)
I: Mhm
P: Because there you can see a person cycling
I: Yes, that is true.
P: Because there you can just try to sit on the bicycle and such things (points to another picture)
I: Yes, there it looks more as they just are getting ready and testing.
P: Mhm
B: But which bicycle have you used?
P: I used that one (points to a hand powered bicycle)
I: Mhm
B: Maybe it is fine that it is a picture of that one as well?
P: Yeees
B: That it is possible
I: Mhm
P: Yes it is!
I: So that you can see that there are..., so one can see, if one looks as these before one arrives here, one can see that we have many different bicycles.
P: Mhm
I: Mhm
P: So, maybe this one then? (points to a picture)
I: Mhm?
P: Yes
I: What would answer one this one using the smileys?
P: Ehm, maybe want to.
I: Yes......Good
I: Let’s see, there pictures of many different things, and that is because we want you to be able to do many different things when you are here.
P: Mhm
I: Can you see what these people are doing?
P: Ehhm, I am not quite sure.
I: No...
I: Can you see that all of the things have wheels one them? That everybody is doing something on wheels?
P: Mhm, ehhm, ...
I: Would you have like to try this, or is it difficult to see what you can try?
P: Difficult to see what one can try
I: Mhm
P: Especially on those ones (Points to two of the pictures)
I: I agree with you...
I: But is it possible to see what these people are doing?
P: Ehm...Ehhm...Yes, this one (points to one of the pictures)
I: Mhm
P: That one does not see..ehm that one shows better (points at two of the pictures)
I: Mhm
P: One can see something, like you can see what they are doing.
I: Yes, what are they doing here?
P: Emh, he is shooting an arrow at a...thing that you are supposed to shot an arrow at in a computer game.
I: Mhm, are those also playing computer games?
P: It looks like it
I: Yes, what would you answer on this one?
P: Very much would like to.
I: @ Yes, that is good. We will try to get more computer games, because we believe that many children would like to use them...
I: Can you see what they are doing?
P: Ehm, they are climbing
I: Yes
P: mhm
I: Mhm, what would you answer on this one?
P: I would answer that one (points to one of the pictures)
I: And what if you were to answer by smileys?
P: mumbles
I: What?
P: Would not want to
I: No...
I: Let us see...
I: Have you been in here?
P: Yes I have been there
I: Yes
I: Do you know what the room is called, where this picture is taken, and what you can do in there?
P: Ehm, the gym.
I: Yes
P: And training
I: Mhm
P: Ehhm....
I: Would you answer the red one, the yellow or the green if we asked you if you wanted to do this?
P: I would have answered yellow.
I: Yes, want to a little?
P: Yes
I: Yes....
I: So then, can you see what different things these are doing, or some of them?
P: Yes, I can see that one this one they are playing table tennis. (points to one of the pictures)
I: Mhm
P: And they are playing boccia. (points to another picture)
I: Very good
P: And golf (points to the third picture)
I: Yes
I: And you knew golf as well?
P: Yes
I: Had you answered..what would you have answered with the smileys on these ones?
P: I would have answered: would very much have liked to.
I: Yes, that is good. Then maybe we are able to find some activities that you like?...
I: What are these people doing?
P: Hmmh...What is this...
I: Mmmm
P: He is about to throw a basketball in a basket on this one. (points to a picture)
I: Mhm
P: And is is driving el floorball (points to another picture)
I: Mhm
P: And….and this is ice pigging (points to the third picture)
I: Yes, so they are playing team sports?
P: Yes
I: Mhm
I: What would you answered one this one using the smileys?
P: Ehh.Would very much like to
I: Then we have one... then we are getting close, it is not that many left
I: Ehmmm... Can you see what they are doing? These pictures were a bit small so I have to get some bigger pictures, it wasn’t that easy to see.
P: It looks like they are dancing maybe?
I: Very correct, yes they are
P: Here I am very unsure
I: Yes, I agree with one that
P: Here it looks like they are going to drum with sticks on rubber balls
I: Yes, they are playing drums on rubber balls.
P: Playing drums on rubber balls.
I: Mhm
I: Would you like to do that, or would you answer?
P: Maybe want to
I: Maybe
I: Let’s see, and here there are some that are stapled together, here is one picture, there is one
P: Hmm
I: What do you think they are doing?
P: Looks like they are having an outdoor activity of some kind
I: Very correct, they are doing some outdoor games
P: Mhm
I: What would you answer on that one?
P: Maybe
I: Maybe..
I: Great, let’s see...
I: In then there are these ones…. Can you see what they are doing?
P: This is…some kind of hiking in the mountains (points to a picture)
I: Mhm
P: Here they are walking a trip (points to another picture)
I: Yes
P: And here there are people that…I actually don’t know (points to the third picture)
I: They are also going for a walk, but they are having a break, but it is maybe
difficult to understand that they are going for a walk as they are sitting?
P: Yes, that is true
I: Mhm
I: Would you have wanted to do that or would you have answered?
P: I would have answered ehhh would very much like to
I: Yes, let’s see….and then there is…what are they doing?
P: ….Here it looks like they are making a fire (points to a picture)
I:Mhm
P: And they have some pots on top, and there is a guy in a wheelchair (points to
another picture)
I: Yes
P: And here is one that is fishing, and here they are cooking
I: Mhm
P: And here is a can, and more cooking (points to the third picture)
I: Would you have liked to do these things?
P: Yes
I: Do you think you would answer green, or yellow or?
P: I would have answered green
I: Yes, that is good
I: Then there’s four activities left..Can you see what they are doing?
P: Yes
I: Yes, that is good

P: They are sitting in a canoe on this one, (points to a picture)
I: Mhm

P: And canoe here, and canoe there (points to the second and third picture)
I: Mhm, very correct

P: I would have answered green!

I: @ So great, have you been a lot down at the lake?

P: Yes, we have been there two times

B: What kind of other boats are there down there?

P: Kayak

B: Kayak, yes. Can you see that here?

I: No, that a little bit bad that we do not have a picture of

B: Maybe we should have that?

P: Yes, we should!

B: So that one can see that that also is a possibility

I: What do you think that these pictures shows that you can do?

P: Making a snow cave (points to one picture)
I: Yes

P: Play a parachute game (points to another picture)
I: Mhm

P: Make a snow sculpture (points to the third picture)

I: Would you like to do that if you were here in the wintertime?

P: Yes

I: Yes, green or yellow or what do you think you

P: Yellow

I: Yes

I: These then?

P: ......Ski cart, skis, skis (Points through all three pictures)
I: Mhm

P: Maybe

I: Maybe, that is great. Then we are at the last one...let's see

I: What are they doing?

P: Is that slalom or?

I: Yes, that is correct, it is
P: Slalom, slalom and slalom (Points through all three pictures)
I: Mhm
P: eh, red
I: yes, so you might have wanted to do cross-country skiing but not slalom?
P: No
I: At last, is there any activities that I have not asked you about, that you would have like to do here?
P: No..
I: No, that is good
I: You have done great; I would like to thank you very much for your help
P: You’re welcome
I: And maybe, if you come again, you can see some of these pictures on the internet before you come
P: Mhm
I: And you can answer, so that we know what you want and can prepare for that before you are coming
P: Mhm
I: Thanks again, goodbye

Transcription Interview 2.
I= Interviewer  @= laughter
P= Participant  ? Question intonation
B= Bi-sitter  ! Clear and fast answer
Nods and pointing described in the text

I: My name is Lars Kristian, so what I want to ask you today is which activities you like to do?...i..Do you remember that before you came here, you answered a survey on the internet with smileys?
P: Yes
I: Good, and then I would like to show you some pictures to find out if the activities we are asking you about are the one that you do or don’t want to do.....I will be
recording what we are talking about on my telephone, that is to remember correctly what we talked about,

P: Okay

I: And if you want to quit the interview at any time, and do not want to participate anymore, you can just tell me at any time, and you can leave

P: Yes

I: And no answer is wrong or correct, and we do not write your name on any of the answers

P: Yes, ok

I: So we can only see the answers, and not whom that have answered what.

I: I work a lot with planning what you are going to do when you come here, so that is why I would like to ask you what kind of activity you like, and if we ask about the activities you like and such thing?

P: Yes

I: What do you think have been the most fun to do while you have been here?

P: Ehh...I don’t know

I: No?

P: Being in the swimming pool

I: The swimming pool?

P: Yes

I: Mhm

I: Is there anything that not have been funny?

P: No, nothing

B: You are allowed to answer even if I am sitting here @

I: Yes

B: Just so that you know

I: Mhm

I: why is it so that some activities are more fun to do than others are?

P: I like better to do things that I am good at

I: Right, I agree with you, I also like better to do things that I know how to do

I: Do you get to take part in the decisions about what you are going to do while you are here or have we decided everything?

P: No, I am able to be part in the decisions

I: That is great
I: ehhm... are there any activities that are easier to do here than at home?
P: Ehhm.. The gym
I: Mhm
P: Different activities there
I: Is that maybe because it is not so easy to find a gym at home?
P: Yes
I: Do you think that you will continue to do anything of what you have done here when you come home?
P: ..Swimming, I also did that before.
I: Yes, that's good.
P: So I am going to continue doing that
I: What do you think when you see these pictures of these smileys? Are they different in any way, do you think anything different between the green, the yellow and the red one?
P: That you don’t want to, that is the negative one, sort of say
I: Mhm, that’s correct
I: Then I am going to show you a lot of pictures of people doing various things
P: Yes
I: I then I want to know if you can see what they are doing in the pictures
P: Yes
I: And if want you to say if you would answer yellow, green or red on them
P: Yes
I: Can you see what they are doing?
P: Ehhhh
I: You don’t need to say exactly what they are doing, but only which activity they are doing is great.
P: Ehhh, he is floating, training to float
I: Mhm
P: Swimming through a ring under water
I: Yes
P: And here they are throwing a ball
I: Very good, great...what would you answer on this one?
P: No...very much would like to
I: Yes, that’s good.
I: These then, can you see what they are doing?
P: Ehhm, they are riding, what’s it called….horse and carriage I was about to say
I: Absolutely correct
P: And here is tidying up in the stable, and caring for the horses
I: Mhm, what would you have answered on this one?
P: Well I have ridden before, and was not a big fan, so I would not like to do that
I: @ No, I have tried it once as well and didn’t like it, so I would have answered the same as you
I: Can you see what they are doing?
P: They are climbing
I: Mhm, that’s good
I: What would you have answered on that?
P: Emhhh, would very much have liked to, I went to climbing earlier
I: Oh, so you have done it earlier as well?
P: Yes
I: Have you been able to do some climbing while you have been here?
P: No, I am still in rehabilitation for a broken leg
I: Oh yes, that’s right
I: Is it possible to see what these are doing?
P: Ehh…Playing some games it looks like.
I: Mhm, yes…..if we had more of these what would you have answered on this?
P: That would have been fun
I: Yes, that’s great
I: Is it possible to see what these are doing?
P: …It is like wheel…no what is it called
I: Yes…..
P: Activities on wheels
I: Very good, great, what would you have answered on this one?
P: Ehhh..I would not have liked to do those two, but that one would be an option
I: Training some wheelchair technique, riding over obstacles and such?
P: Yes
I: That’s good
I: And then there’s one where it might be easier to see what they are doing?
P: Riding bicycles
I: Mhm
I: What would you answer on that one?
P: No, I would not like to do that really
I: No
P: I don’t think it's funny to cycle
I: No...lets see
I: Is it possible to understand from these pictures what they are doing?
P: Ehh...playing table tennis, it is different ball sports
I: Yes, it is..what would you have answered on that one?
P: Ehh....what is it...would very much like to
I: That’s good
I: And now...we are about halfway through the activities...lets see
I: Can you understand what these are doing?
P: Eh...are they pigging? Pointing to a picture
I: Mhm
P: Playing hockey in wheelchairs pointing to another picture
I: Yes
I: And throwing. No...are they throwing balls? Pointing to third picture
I: Yes....so they are kind of doing various team sports
P: Mhm
I: What would you have answered on that?
P: No, it would have been fun to try, so maybe
I: Maybe want to?
P: Yes
I: That’s good....
I: Have you been in this room, so that you know?
P: Yes
I: Yes
P: Eh...I would very much like to do that, it is the gym
I: Yes, and you like that?
P: Yes
I: That’s good, then Henrik (B) must have found some good exercises for you to do in there
P: Yes
I: Mhm
I: This might be a bit more difficult to see, because the pictures are a bit small? It is that one
P: Looks like they are balancing...It is playing outdoors
I: Yes, that’s correct...what would you have answered on that one?
P: Ahh, maybe want to
I: Yes
P: Try it
I: Lets see, then there are these ones, they are also a bit small, one of them are big
P: Yes..here they are drumming pointing to one picture
I: Mhm...is it possible to see from that picture what they are doing?
P: No.....No, I didn’t understand that
I: I agree with you
P: It is difficult to see
I: It is supposed to show that they are dancing and moving to music.
P: Oh yes
I: But I think that I have to get a new picture that shows it a bit better
I: What would you have answered on that?
P: Yes.., might have wanted to do that also
I: Yes, that’s good
I: Is it possible to see which activity this is, what they are doing here?
P: Here they are out walking
I: Mhm, that’s good, what would you have answered on that one?
P: Maybe want to, on that one also
I: Yes
I: And then there were which activity, they are doing somewhat different activities here, but what they are doing here?
P: Are they fishing? Pointing to a picture
I: Mhm
P: And they are barbecuing outside and such..and yes pointing to the other two pictures
I: Mhm, would you have liked to do that?
P: Yes
I: Would you have pressed yellow or green or?
P: Eh green
I: Yes
I: Then there is something you might have tried while being here?
P: Yes, I would have pressed green, they are paddling
I: Yes that’s good
I: Lets see...and then we will look at some activities that we can do now, but that we could do in the wintertime
P: Oh.ehhh...yes. Looked a bit fun, so might want to
I: Yes
P: Here they are building things from snow
I: Mhm
P: Building snow cave and.
I: Outside playing in the snow?
P: Yes
I: Mhm
I: Then there is this one
P: Here they are going on skis pointing to one picture
I: Yes
P: Here they are pigging pointing to another picture
I: Yes
P: I would very much like to do that
I: That’s good
P: It is pigging for me, that I want to do
I: Mhm, that’s great
I: Then there is the last activity?
P: Here they are going alpine skiing
I: Yes, that’s correct..Would you have liked to do that?
P: No, not so much
I: No , so you would have pressed red on that one?
P: Yes
I: Are there any activity that you would have like to do while you are here that I have not asked you about, are there anything?
P: No, not really
I: No, that’s great
I: You have done really well, and we will use these answers to decide which activities we will have for you, because we want to try to have mostly the activities that you want to do
P: That’s good
I: So we are really going to use these answers further on, so it is very good that you wanted to participate
P: Yes
I: Thanks a lot for your help
P: you’re welcome
B: Good job
I: Mhm
I: Bye
P: Bye

Appendix 5 Interview guide for individual interviews with CAD

Introduction:
We are now going to conduct an interview, a short conversation. Brief description of who
I am. The reason that I want to talk with you, is that I want to find more about which
activities you like and I want to check with you whether the questionnaire you just
answered on the computer was easy to answer and asked about the right activities. Your
answers are important, because this will help us to make the children and adolescents
choose the activities they want to do in the best way.

It is you, children and adolescents between 5 and 18, who are staying at BHC this summer
that I am going to ask these questions.

It is going to take approx. 20 min, and I am going to record this conversation on my cell
phone and take some notes during our conversation. You can stop the conversation at
any time if you don`t want to answer. There are no right or wrong answers to any of the
questions. All answers will also be anonymized, that means that no one would be able to
know what you have told me. Your name will not be used, just a number for each one that
has answered.

Is it anything you would like to ask about before we start?

Part 1: This part will try to answer: What a child participates in, and how he/she feels
about his/her own participation during a stay at BHC I want to find out if the child feels that
he/she has any opportunity to influence on what they are doing, and hope to find out both
what they like to do, and what they don`t like to do. I also want to find out why they like
some activities better than others, and whether they might chose and rate activities
different here than at home.

1. Which activity have you liked the most to do here at BHC, what have been the
   most fun?

2. Is there anything you think has been less fun, anything you haven`t liked to do?

3. Can you say something about why it is like that? Why something is more fun to
do than other things, and why you like something better than other things?

4. Do you get to influence on what you are doing here at BHC?
   Are you a part of deciding what you are doing here? Do we listen to you
   when you are expressing your wishes? Are there room for you to make
   suggestions about what to do, and how to do it?
5. Is there something that is different here at BHC from home that makes you do or want to do other activities? If so, what might that be?
   - With whom?
   - Where you do it?
   - When you do it?

6. Do you think that anything you are doing here at BHC is important for what you can do at home?

**Part 2: This part is to investigate the children’s understanding of the questionnaire.** What are their thoughts about the scale, the smileys? How do they understand/interpret each question/picture? Have they mentioned any activities in part 1 that are not part of the questionnaire? Do they have any ideas for new questions?

1. Can you tell me what you think when you see these smileys?
   What does it mean/what do you want to tell me when you choose the Red one?
Yellow one?

Green one?

2. Questions while going through all Pictures/questions in the questionnaire?
   a. What is this person doing?
   b. Do you think you could do this?
   c. Would you like to do this?
      i. Why? Why not?
      ii. How much would you like/not like to do it?
   d. How would you rate it with smileys?

3. Are there any activities you like to do here that we haven’t talked about?

Then we are finished and I have asked you all the questions I wanted to ask. Is there anything you are wondering about, want to ask me or want to tell?

I think you have done very well and given me important answers. I think it is both important and fun to learn more about what you want to do.

How do you think this was?

Now I am going to remove your name and write all these answers into my computer. Your important answers will help me to understand more about what you children would like to do when you come here to BHC. I will be teaching this also to the other people working here, so that we will be even better to plan activities that you yourself like to do when you come here.

Thank you very much for your help and for that you wanted to talk

Appendix 6 Original REK answer in Norwegian

Forskningsansvarlig: Beitostølen Helsesportsenter

Prosjektleder: Reidun Jahnsen

Prosjektleder: Reidun Jahnsen

Prosjektbeskrivelse

Det elektroniske spørreskjemaet BarnAs 1 er brukt i 2 år ved Beitostølen Helsesportsenter. Det består av 19 spørsømløsørnere som har deltakert aktivitet med smilefjes, nøytralt fjes eller surt fjes i forhold til om og eventuelt hvor lyst de har til å delta i ulike aktiviteter under sitt opphold ved senteret. Man ønsker nå å gjøre en analyse av svarene fra 2015 n=343 for å få kunnskap om hvilke aktiviteter flest ønsker eller ikke ønsker å delta i og om det er variasjoner i dette basert på kjønn, alder eller funksjonsnivå. Bildene inneholder også bruk av aktivitetshjelpemidler for å vise alternative måter å delta i aktiviteter på ut fra funksjonsnivå. Resultatene skal anvendes til å videreutvikle instrumentet, og den reviderte versjonen vil bli undersøkt i en prospektiv studie av psykometriske egenskaper. Utvikling av BarnAS 2 som skal kartlegge hva barna faktisk gør i sitt hjemmemiljø, hvor ofte, med hvem og glede ved deltakelse er en PhD-prosjekt ved Høgskolen i Lillehammer.

Vurdering

Formålet med prosjektet er å evaluere spørreskjemaet BarnAs 1 for å undersøke hvilke aktiviteter ved Beitostølen Helsesportsenter flest ønsker eller ikke ønsker å delta i og om det er variasjoner i dette basert på kjønn, alder eller funksjonsnivå. Komiteen vurderer at prosjektet, slik det er presentert i søknad og protokoll, ikke vil gi ny kunnskap om helse og sykdom som sådan. 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

Klageadgang
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
Kopi til: astrid.nyquist@bhss.no
Appendix 7 Article submitted to “Scandinavian Journal of Nursing Research”

Scoping review of the literature about instruments for mapping activity preferences for children and adolescents with disabilities:

Abstract:
A main goal for health, social and pedagogical service providers is to optimize participation at different life arenas for Children and Adolescents with Disabilities (CAD). Participation based on the individual’s preferences promotes both learning, knowledge of self and a sense of mastery. It is therefore important to have relevant and validated instruments for mapping preferences for activities among CAD.

Aims: To identify literature including relevant instruments for mapping preferences for activities among CAD.

Methods: A comprehensive systematic search was conducted in PubMed, Medline and Cochrane Library. The search was limited to CAD between 5 and 18 years of age. A PRISMA flow chart was developed as a basis for the search, and a review of the search was undertaken by two independent researchers based on an adapted PRISMA chart to ensure that no relevant instruments were missed. Clearly defined inclusion and exclusion criteria for included articles were outlined.

Findings: Seventy-four articles were found in the first search. Fifty-nine did not fulfil the inclusion criteria and were excluded. Fifteen articles were included in the initial review, resulting in further examination of five instruments included after a detailed review of the relevant articles.

Discussion: The results of this search, and evaluation of the instruments found, showed that there is only one relevant instrument available for mapping CAD’s activity preferences, the Preferences for Activities of Children (PAC). The instrument is several years old and needs adaptation fit in to a Norwegian rehabilitation context. This means that some of the activities are not relevant, while other activities that CAD might engage in today are missing. The available instruments are also extensive and may be too difficult for CAD to manage independent administration.

Conclusions: There is a need for the development of a new updated instrument for mapping CAD’s activity preferences in a Norwegian context, and designed in a way that CAD can understand and complete themselves with minimal guidance.

Keywords: Activity, preferences, participation, children, adolescents, disabilities.

Competing interests: nil known

Ethics approval: not required
Background:

A main goal for health, social and pedagogical service providers is to optimize participation at different life arenas for Children and Adolescents with Disabilities (CAD). Engagement in preferred and enjoyable leisure activities are also essential for physical and mental health (Hoogsteen & Woodgate, 2010; Majnemer et al., 2008). Involvement in physical leisure activities gives children and youth in general a sense of belonging, opportunities to fulfil personal goals, and to develop and grow as individuals and physical activity is an essential part of children’s development. CAD are challenged by restrictions to their participation in leisure time activities due to both individual and environmental barriers (G. A. King et al., 2007; Kirsti Malterud, 2003).

The family of participation-related constructs model defines participation in two dimensions; attendance and involvement. Attendance is measured as frequency or diversity of activities; and involvement is defined as the experience of participation while attending. Other personal Intrinsic factors include preferences, activity competence and a sense-of-self. These constructs are not participation per se, but are closely related to participation. Preferences in a paediatric rehabilitation context can be defined as the “subjective elements of how people explain their participation” (Skille & Østerås, 2011). Imms et al, (Christine Imms et al., 2017), define the construct of preference as “The interests or activities that hold meaning or are valued.” (p.20.)

The importance of focusing on preferences in relation to enhancing participation is shown in a newly published conceptual analysis of participation for CAD (Christine Imms et al., 2017). They found that preferences are an important intrinsic factors that influences, and are influenced by participation. Preferences are influenced by our previous experiences, i.e. if we have positive experiences of taking part in an activity or meeting with a person or group of people, the chances will increase that we would like to do the activity or meet the person(s) again. The environment will also have an impact on our preferences, for example entering a gym that is appealing and easily accessible will probably set it above another options. Consequently, preferences can predict our future actions of participation (Christine Imms et al., 2017).

Assessing preferences is also essential in the process of collaborative goal setting. Palisano et al (Robert J. Palisano et al., 2012) found that service delivery is ideal when it is goal-oriented, family-centred, collaborative, strengths-based, ecological and self-determined. It is also found, in randomized controlled studies, that a goal-directed approach of practice of real tasks in real or natural environments are both more effective than no therapy (Novak, Cusick, & Lannin, 2009) and more effective than general therapies, which focus on impairments of movement and muscle performance (Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Salem & Godwin, 2009; Van Den Broeck et al., 2010).

Consequently, when considering implementing efficient interventions to optimize participation in physical activities, it is important to consider the complex interaction of individual characteristics, such as functional level and motivation, and physical and social environmental factors. The interventions need to be family-centred, where children, youth, and their families are actively involved in the entire rehabilitation process (An & Palisano, 2014).
Participation goals for rehabilitation interventions must be sufficiently challenging, neither too easy nor too hard to achieve, but give a sense of manageability (Eriksson & Lindstrom, 2007). Another reason why it is important that the goals are child and family determined and meaningful, is because goal attainment and opportunities to make choices enhance the intrinsic motivation to engage in specific activities and stimulate beneficial rehabilitation outcomes (Abuhamdeh & Csikszentmihalyi, 2012; Deci & Ryan, 2000). Research undertaken by Koestner and Losier (Koestner, Losier, Vallerand, & Carducci, 1996) showed that intrinsic motivation yielded better performance on tasks that were interesting. Bult et al. (Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2014) found that CAD had significantly lower preferences for activities than typically developing children. The reason for this might be that they lack experiences from activities, and therefore do not have enough experiences with which they can link preferences. Another reason might be that they are not aware of their opportunities. Thus, it is essential for service providers to focus on the participation of families or families’ preferences for activities, and support the parents in engaging in all kinds of activities with their children.

Few empirical studies describe the contextual and methodological features considered when implementing interventions to improve participation in leisure activities of CAD. One reason might be the informal and not standardized processes for goal setting and implementation of rehabilitation strategies and the lack of adequate ways of evaluating outcomes of participation.

Participation based on the individual’s preferences promotes both learning, knowledge of self and a sense of mastery (Bandura, 1993), all essential factors in successful rehabilitation. It is also known that preferences are an important predictor of participation in leisure activities (C. Imms, Reilly, Carlin, & Dodd, 2009; G. King, Law, Petrenchik, & Hurley, 2013; Shikako-Thomas, Majnemer, Law, & Lach, 2008). Leisure participation is important for CAD’s development and well-being, and increased participation on various life arenas is the main goal of many services providers working with CAD.

Experiences and needs for instruments mapping preferences and participation in a residential rehabilitation setting

Beitostolen Healthsport Centre (BHC) is a residential facility that offers intensive rehabilitation services, in a group setting, based on a family-centred approach for children and youth with a range of disabilities. Adapted physical activity is the main intervention. At BHC, goals have been defined by CAD and their families by using the Canadian Occupational Performance Measure (COPM) (Dedding, Cardol, Eyssen, Dekker, & Beelen, 2004). Following the rehabilitation period, the children and adolescents set goals related to participation in physical activity in their local community using the Goal Attainment Scaling (GAS) (Steenbeek, Ketelaar, Galama, & Gorter, 2008). These goals are meant to be achieved within their own community context and are followed up after three months. However, in our clinical practice these two individualized instruments (COPM and GAS) are often experienced as too abstract and not user-friendly for CAD.

In a PhD project at BHC Astrid Nyquist (A. J. Nyquist, 2012) used The Children’s Assessment of Participation and Enjoyment (CAPE) (Gillian King, 2005) and the Preferences of Activities
in Children (PAC) (Gillian King, 2005) for mapping CAD’s preferences for leisure activities, enjoyment in activity, and participation profile. This was done both before, three months after (Nyquist, Moser, & Jahnsen, 2016), and one year after a stay at BHC (Baksjøberget, Nyquist, Moser, & Jahnsen, 2017). The participation profile contains variables, such as diversity of activities, frequency, enjoyment and contextual factors, such as where and with whom the activities where performed. Translation into Norwegian and reliability testing of CAPE & PAC for mapping and evaluation in a Norwegian context was conducted, and showed satisfactory results for clinical and research use (H. L. Nordtorp et al., 2013). However, because of restrictions put in place by the publisher, who would not publish the Norwegian version due to a too small a market, the Norwegian version could not be widely disseminated.

Based on extensive clinical use, the scaling of the original version also proved to be too difficult to understand for many of the children without substantial help and guidance from parents or personnel. The instrument is nearly 15 years old, and many of current activities CAD participate in are missing, i.e. martial arts and virtual reality training and gaming. There were also few winter activities, which are particularly important in Norway. Therefore, there is a need for a modified, updated and validated instrument to evaluate preferences for participation in activities of CAD in a Norwegian habilitation context.

The aim of the present review was to systematically investigate the availability of instruments that can be used to assess preferences for activities of CAD aged 5–18 years. This age range is specified, as it is a time for children to develop activity competences and gradually become autonomous in participating in life situations (Pehoski & Henderson, 2006). The psychometric properties and clinical utility of potential instruments will be assessed. The results of this scoping review could provide a useful guide for selection of appropriate measures to evaluate activity preferences. We assume that there might be a lack of such measures in the existing literature, and an alternative would be to modify the PAC into a feasible, valid and reliable instrument in Norway.

Procedure:

An initial search was done to find the relevant search words, index words and free text words. A comprehensive search was conducted in PubMed, Medline and Cochrane Library. A PRISMA flow chart was developed as a basis for the search. A review of the search was done by two independent researchers based on an adapted PRISMA chart (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) to ensure that no relevant instruments where left out. Both researchers concluded with the same findings, and located the same five instruments. Clearly defined inclusion and exclusion criteria for the instruments found were set. The instruments that met the inclusion criteria were further examined.

Inclusion criteria:

The inclusion criteria were set according to important features of the instrument that is needed. These were:
1. The target population included CAD aged 5-18 years;
2. The instrument was used in field-based studies involving CAD;
3. The study involved both a dimension of activity and a dimension of preferences, and
4. CAD should be able to understand and report in the instrument themselves.

After the first search, it became evident that these criteria were too narrow. Children’s Assessment of Participation and Enjoyment and Preferences for Activities of Children (CAPE/PAC) – (Gillian King, 2005), were the only instruments that met all the criteria. The criteria were then revised to include articles about mapping activities for CAD with an extra dimension containing enjoyment and/or preferences. After this search was conducted, the instruments found were evaluated according to the original criteria as they represent the practical needs that the instrument is meant to cover.

**Search mesh terms in PubMed were:** Disabled persons (includes sub-category of Disabled children), Motor skills disorder, Adolescent (=13-18 years), Child (=5-12 years), Pediatrics, Motor Activity, Patient preference, Leisure Activity. Mesh terms covering most of the same sub-categories were used in the other databases.

**Free-text terms were:** Disab* (covers physical, childhood developmental, intellectual, disabled person), “Special ADJ1 needs”, Adolesc*, Youth*, Child*, Teenage*, “Young adult*”, Paediatric* OR pediatric*, Physical activity, Child*+preferences”, Adolescent*+preferences, Measuring child* preference, Measuring adolescent* preference.

**Results:**

Figure 1, a modified Prisma Flow Chart (Moher et al., 2009) demonstrates the relevant articles found and the screening process that followed. A total of 78 relevant articles were located, amongst these, 22 duplicates were removed. All abstracts were read for the remaining 56, leading to the removal of 29 articles due to lack of relevance, as they did not include validated instruments or only included peer-reported questionnaires. Twenty-seven articles were read in full text, removing 12 more, as they had no relevant information not covered by other articles. Five instruments were identified based on the remaining 15 articles.
Records identified through database searching (n = 74)

Additional records identified through other sources (n = 4)

Records after duplicates removed (n = 56)

Records screened (n = 56)

Records excluded, lack of relevance (n = 29)

Full-text articles assessed for eligibility (n = 27)

Full-text articles excluded, did not fulfil the criteria (n = 12)

Studies included for closer review of the instruments (n = 15)

Figure 1. Flow chart of the included articles in the scoping review.
The 15 articles included five instruments that potentially fulfilled the inclusion criteria. Table 1 presents the 15 articles and the instrument that are described in these papers.

**Table 1. Articles including potential instruments on activity preferences of children and adolescents with disabilities**

<table>
<thead>
<tr>
<th>Studies</th>
<th>Instruments</th>
<th>Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kendzierski, D., &amp; DeCarlo, K. J. (1991) (Kendzierski &amp; DeCarlo, 1991)</td>
<td>Preferences</td>
<td></td>
</tr>
<tr>
<td>Aggio, D., Fairclough, S., Knowles, Z., &amp; Graves, L. (2016) (Aggio et al., 2016)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Physical Activity Enjoyment Scale, **Activities Scale for Kids, ***Children’s Assessment of participation and enjoyment/ Preferences for Activities in Children, Physical Activity Questionnaire – Adolescents/Children****, Preschool-age physical activity questionnaire*****
Evaluation of instruments according to the original inclusion criteria:

**The Activities Scale for Kids (ASK)** (N. L. Young, J. I. Williams, K. K. Yoshida, & J. G. Wright, 2000)

*About the instrument:*

The ASK is a self-reported measure of disability for children between the age of 5 and 15 years. It is developed in two versions, the original version, the Activities Scale for Kids (ASK), and the Activities Scale for Kids performance version (ASKp). The original version measures what the child could do during the previous week (capability), while the performance version measures what the child did do (performance).

The ASK contains 30 items that are aggregated into one overall sum score. There are seven sub-domains: personal care, locomotion, dressing, other skills, play, standing skills and transfers. The ASK reflects the children’s perspectives of disability and it provides the option of examining performance and/or capability. It is a useful instrument for exploring the nature of children’s activity limitations. The ASK has excellent reliability (ICC=0.97) and the validity was demonstrated by a correlation of 0.81 (P<0.0001) with parent-reported Childhood Health Assessment Questionnaire scores; a significant difference in scores according to clinicians global ratings of disability (P<0,0001), and a correlation of 0.92 (P<0.0001) with clinician observation. (Nancy L. Young et al., 2000).

*Evaluation in relation to inclusion criteria:*

The ASK and the ASKp are mainly focused on daily activities and not on leisure time activities or physical activities. It also lacks the desired dimension of preferences. Palisano et al (R. J. Palisano, Copeland, & Galuppi, 2007) has used the ASKp to show that the motor abilities of adolescents with CP influenced their participation in physical activities.

**Physical Activity Enjoyment Scale (PACES)** (Kendzierski & DeCarlo, 1991).

*About the instrument:*

The PACES is a survey instrument used to measure enjoyment of physical activity. The instrument consists of 18 items assessing exercise enjoyment. The instrument is also available in a shorter version, Physical Activity Enjoyment Scale Short Form. (Paxton et al., 2008)

The instruments validity has been tested in measuring enjoyment of physical activity in adolescent girls (Motl et al., 2001), and another study has looked at the factorial validity and gender invariance in older adolescents. (Dunton et al., 2009)

A revalidation of the instrument have also been done in 2014 (Zhou et al., 2014) and this is the most recent validation. They found, through confirmatory factor analysis, that the construct validity of the original scale and fit indexes were not within acceptable range (i.e., goodness-of-fit index = 0.72, adjusted goodness-of-fit index = 0.64, and root mean square error of approximation = .12). The scale was then revised, and the revised scale consisting of 2 domains showed acceptable validity and reliability. Cronbach’s alpha for the entire
revised scale was 0.96 while the alpha for the domain of perception and antecedent of enjoyment was 0.9 and 0.95 respectively.

**Evaluation in relation to inclusion criteria:**

The instrument is validated among most of the target age group. It does not have the properties to measure new activities that have not been tried yet. It is also too difficult for the younger children to self-report.

**Physical Activity Questionnaire for Adolescents (PAQ-A)** – (Kowalski, Crocker, & Kowalski, 1997)

**About the instrument:**

This is a modified version of the Physical Activity Questionnaire for Older Children (PAQ-C) (Kowalski, Crocker, & Faulkner, 1997). Both these instruments measure physical activities during the last seven days. There are nine different questions that ask about the type of activity, what the respondent has done at lunch, about physical activity right after school, in the evening, on the weekend, and how much of the spare time that was used for physical activity. There is also one question about sickness during the past week. The instruments were modified and validated in 2016 (Aggio et al., 2016). This process revealed that the original instruments were unrepresentative for English youth, and that item comprehension varied. After contextual and population/cultural-specific modifications were made, the modified instruments had acceptable internal consistency (α=.72) and test-retest reliability (ICC= .78).

**Evaluation in relation to inclusion criteria:**

There are no questions regarding preferences for activities, neither before nor after doing the activities. In addition, the questionnaire is difficult for children to fill out on their own.

**Preschool age physical activity questionnaire (Pre-PAQ)** (G. M. Dwyer et al., 2011)

**About the instrument:**

This instrument is a 3-day activity questionnaire, which is designed to measure habitual physical activity and sedentary behaviour in the child’s home environment. Pre-PAQ is meant to be used during one week-day and two weekend days. It has a list of activities typical for the age group and asks YES or NO related to each activity, if yes, the time spent on the activity is also to be recorded. It also has a section-measuring parents’ level of physical activity. The instrument has acceptable validity and reliability where the answers ranged from 0.31-1.00 for continuous measurers and from 0.60-0.97 for categorical measures. (G. M. Dwyer et al., 2011)

**Evaluation in relation to inclusion criteria:**

There are no questions regarding preferences for activities, neither before nor after doing the activities. The instrument is designed for parents to fill out, and it is long with some complicated questions. Thus, it does not fulfil the inclusion criteria.
Children’s Assessment of Participation and Enjoyment and Preferences for Activities of Children (CAPE/PAC) – (Gillian King, 2005)

About the instrument:

The CAPE is a self-report measure of participation for CAD aged from 6-21 years. It includes both formal and informal domains. It measures five activity types: recreational, active physical, social, skill-based and self-improvement (King et al. 2004; 2006b), that are again divided into 49 specific activities. The CAPE assesses five dimensions of children’s participation in recreation and leisure activities (diversity, intensity, location, companionship, and enjoyment). The conceptual strengths of the CAPE include its measurement of multiple dimensions of participation (Christine Imms, 2008). CAPE also measures the enjoyment of an activity on a scale from 1-5.

The PAC (Gillian King, 2005), is used to assess children’s self-reported preferences for recreational, active physical, social, skill-based and self-improvement activities. It is widely used among CAD’s as i.e. to describe leisure activity preferences for 6- to 12-year-old children with cerebral palsy. (Majnemer et al., 2010). Activity preferences are scored on a 3-point scale also represented by smileys (1 = would not like to do at all, 2 = would sort of like to do, 3 = would really like to do). The PAC is translated into various languages and validated in various contexts and populations; it has i.e. been validated in among children with high functioning autism (Potvin et al., 2013). The author of the instrument has done a construct validation (G. A. King et al., 2007). The Norwegian versions demonstrates both internal consistency and sufficient test-retest reliability and content validity, the alpha values for internal consistency varied between 0.53 and 0.87 for the CAPE and between 0.75 and 0.93 for the PAC. ICC was from 0.49 to 0.83 for the CAPE and 0.85 for the PAC (H. L. Nordtorp et al., 2013).

Evaluation in relation to inclusion criteria:

CAPE measures participation in activities and how much the various activities are enjoyed. PAC is the only instrument found that to a certain extent matches all the inclusion criteria. The only criterion that is not fully met is:

“CAD should be able to understand and report in the instrument themselves.” While this is possible for the older children and adolescents, PAC is too long and complicated for the youngest children in the target group. Many of the activities are no longer relevant for today’s CAD’s as the instrument is over 12 years old. There are also relevant activities in a Norwegian context that are missing, particularly winter activities

Discussion:

After reviewing the literature, we identified five potential instruments for mapping activity preferences of CAD, but none of the instruments was found to fully match all the needs described in the inclusion criteria. Preference does not seem to be a well-defined term in relation to this setting, and The PAC (Gillian King, 2005) was found to be the only instrument that measured preferences by self-reporting in the target group. There seems to be no or little focus on instruments where CAD’s own voices are heard. When preferences are mainly are described by observing adults, this may leave room both for interpretation and misunderstanding.
The instrument that met most criteria The Cape and The PAC (Gillian King, 2005), is widely used all over the world. This indicates the need for an instrument that is able to measure CAD’s preferences in a valid and reliable way. However, PAC, is extensive, somewhat dated, and lacks many of the recent activities that CAD participate or could participate in today, and in a Norwegian context a diversity of winter activities is missing. The wording of the questions asked in PAC is also complicated for small children; “If you could do anything in the world, would you …?”. In our clinical practice at BHC, we experience this to be too abstract for our participants. The instrument is also not digital, and requires quite a lot of patience and explanation for CAD to fill out.

Since the PAC will not be published in Norway a modified and digital version has been trailed in collaboration with Gillian King, called BarnAS 1 (means Children’s 1). Instead of drawings, photos of relevant activities in the rehabilitation setting at BHC are used. The photos also show alternative ways of performing the activities, i.e. alpine skiing can be performed standing or sitting. The children are asked a simple question one month before arriving at BHC; “If you had the possibility, would you like to try this activity?” The answer alternatives are the same as I PAC.

Two other Norwegian rehabilitation centres also want to try this modified instrument for activity references, however, in different target groups and activities. Probably the BarnAS 1 could be developed into a generic instrument where the activities can be changed according to the context. A feasibility study in three Norwegian rehabilitation centres will be conducted, and if this proves favourable, further investigation of psychometric properties will be conducted in the different contexts.

Conclusion

The conclusion of this review is that there is a lack of an eligible instrument for mapping activity preferences in CAD in Norway, reported by the children themselves. Thus, there is a need for development of a modified and feasible instrument to fulfil this aim in this target group. There is also a need for a further examination of the term preferences in this group and how preferences relate to participation and the outcome of rehabilitation.

References:


validation of the CAPE and PAC. *Child Care Health Dev*, 33(1), 28-39. doi:10.1111/j.1365-2214.2006.00613.x


Appendix 8 Questions in the revised version of BarnAs 1

How much would you like to?

<table>
<thead>
<tr>
<th>Question nr</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Be in the Pool?</td>
</tr>
<tr>
<td>2</td>
<td>Ride/drive tend to horses?</td>
</tr>
<tr>
<td>3</td>
<td>Bicycle?</td>
</tr>
<tr>
<td>4</td>
<td>Try activities on wheels?</td>
</tr>
<tr>
<td>5</td>
<td>Use VR and sensor based computer games for training?</td>
</tr>
<tr>
<td>6</td>
<td>Climb?</td>
</tr>
<tr>
<td>7</td>
<td>Train in the Gym?</td>
</tr>
<tr>
<td>8</td>
<td>Do individual sport/activity?</td>
</tr>
<tr>
<td>9</td>
<td>Do team sports?</td>
</tr>
<tr>
<td>10</td>
<td>Move to music?</td>
</tr>
<tr>
<td>11</td>
<td>Play/play games outdoor?</td>
</tr>
<tr>
<td>12</td>
<td>Go/roll for a trip?</td>
</tr>
<tr>
<td>14</td>
<td>Do outdoor activities?</td>
</tr>
<tr>
<td>15</td>
<td>Do water activities outdoors?</td>
</tr>
<tr>
<td>16</td>
<td>Play in the snow?</td>
</tr>
<tr>
<td>18</td>
<td>Go skiing/ski-pigging?</td>
</tr>
<tr>
<td>19</td>
<td>Go Alpine skiing?</td>
</tr>
</tbody>
</table>
Appendix 9 Example of the answer form the multi-disciplinary team can print after a child has answered the questionnaire at home

<table>
<thead>
<tr>
<th>Barnas - svar</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Være i basseng?</td>
<td>2. Ri, kjære, stelle hest?</td>
</tr>
<tr>
<td>5. Øve på rullestolteknikk?</td>
<td>6. Klatre</td>
</tr>
<tr>
<td>7. gjøre egentreningstrene på treningssom?</td>
<td>8. Prøve individuell idrettsaktivitet?</td>
</tr>
<tr>
<td>15. Drive med vannaktivitet ute?</td>
<td>16. Løke i sneen?</td>
</tr>
<tr>
<td>17. Prøve aktiviteter på is/sne?</td>
<td>18. Gå/pigge på ski?</td>
</tr>
<tr>
<td>19. Kjære alpint?</td>
<td>Annet:</td>
</tr>
</tbody>
</table>