Inland Norway
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Friedolin Steinhardt

# ‘How can I participate’ – Development of ActiveYou II

## Development of a new web-based, self-reported instrument to measure participation in physical leisure activities for children and youth with disabilities

PhD Dissertations in Child and Youth Participation and Competence Development • 2021

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Development of a new web-based, self-reported instrument to measure participation in physical leisure activities for children and youth with disabilities

PhD Thesis

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## Summary

Participation in physical leisure activities and sports plays an important role in the overall development and well-being of children and youth. The participation pattern of children and youth with disabilities differs from their non-disabled peers. Therefore, optimising participation has become one of the main goals for rehabilitation interventions, Valid instruments to measure the participation patterns, including facilitating and hindering factors are currently unavailable in the Norwegian setting.

Aim of this thesis was to develop a web-based self reported instrument of participation: ActiveYou II

The process followed a in three phases, which adapted different interview-methods and a scoping review. In the first phase a scoping review was performed to explore the constructs of involvement and engagement, which represent the subjective aspects of participation. Thirty-seven publications from different fields of research were included. The results point to define involvement as the personal level of interest, motivation or arousal towards an activity, and engagement as the individual's behavioural, cognitive, and affective investment during role performance. In the second phase, facilitating and hindering factors for participation were explored. Group interviews with children, parents, and professionals were conducted. The results showed that children focused on enjoyment and positive peer relationships as facilitators for participation. Parents and professionals talked about how the individual physical, cognitive, emotional, and social abilities of the children affected participation. Crucial factors for participation were the relationship with and support from parents, and the knowledge and attitude of activity leaders or professionals in the home environment. In the third phase, the first version of ActiveYou II was tested using cognitive interviews with children. Children articulated problems with comprehension and responding to different questions, mainly connected to formulations the children did not understand, or answer alternatives that were not clear enough or they were missing. ActiveYou II was then adjusted for further steps in development.

Summarized, this thesis covers several fundamental steps of the development of ActiveYou II. Further testing of psychometric properties is needed. In addition, the thesis contributes to the discussion on the understanding of the participation construct in the International Classification of Functioning, Disability, and Health (ICF) and the importance of including the perspective of children when exploring a topic concerning them.

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Friedolin Steinhardt

Elverum, June 2021

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Article 2: Friedolin Steinhardt, Anna Ullenhag, Reidun Jahnsen & Anne-Stine Dolva (2019): Perceived facilitators and barriers for participation in leisure activities in children with disabilities: perspectives of children, parents and professionals, *Scandinavian Journal of Occupational Therapy*, 28:2, 121-135, DOI: 10.1080/11038128.2019.1703037

Article 3: Friedolin Steinhardt, Reidun Jahnsen, Anne-Stine Dolva & Anna Ullenhag (2021): Testing ActiveYou II: Applying Cognitive Interviews in Improving Item Quality and Applicability of a Web-Based, Self-Report Instrument on Participation in Children with Disabilities. *Int. J. Environ. Res. Public Health*, *18*, 4768. https://doi.org/10.3390/ijerph 18094768

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## Abbreviations

| | |
|---|---|
| ADD | Attention deficit disorder |
| ASD | Autism Spectrum Disorder |
| BHC | Beitostølen Healthsports Center |
| CAPE | Children's Assessment of Participation and Enjoyment |
| CDC | Centers for Disease Control and Prevention |
| COPM | Canadian Occupational Performance Measure |
| COSMIN | COnsensus-based Standards for the selection of health Measurement INstruments |
| CVI | Content Validity Index |
| EUR | Euro |
| fPRC-model | Family of Participation-Related Constructs |
| ICD | International Classification of Diseases |
| ICF | International Classification of Functioning, Disability and Health |
| ICIDH | International Classification of Impairments, Disabilities and Handicaps |
| ICT | Information and Communications Technology |
| IRT | Item Response Theory |
| KR-20 | Kuder-Richardson-20 |
| MIS | Modified Involvement Scale |
| MET | Metabolic Equivalent |
| NOK | Norwegian Krone |
| PAC | Preferences for Activity of Children |
| PEM-CY | Participation and Environment Measure for Children and Youth |

| | |
|---|---|
| PES | Participation Experience Survey |
| PRISMA-ScR | Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews |
| UN | United Nations |
| UNCRC | United Nations Convention on the Rights of the Child |
| VAS | Visual Analogue Scale |
| WHO | World Health Organization |

# 1

## 1. Introduction

Looking back to one's childhood and youth, almost everyone retains positive memories of their favourite leisure activities and hobbies, no matter whether these are connected to the football pitch, horse barn or excursions into the 'wild' with one's scouting group. Personally, most of my youth memories are in some way connected to activities surrounding my martial arts training – be it training in the dojo, travelling to seminars with our Japanese Master, competing or my first experiences as an assistant coach for children. Research has shown that these are more than 'nice memories', as participation in leisure activities, especially physical activities, with others has various positive effects on physical, mental, and social development and overall well-being (M. M. Bedell, Khetani, Cousins, Coster, & Law, 2011; Bult, 2012; Chien, Rodger, Copley, & Shorka, 2014; Imms et al., 2016; Jahn & Senf, 2006; Khetani, 2011; G. King et al., 2003; Law et al., 2013).

The World Health Organization (WHO, 2018b) recommends 60 minutes of daily moderate physical activity for children and youth 5–17 years old to promote health. As a youngster, I neither knew nor cared about these scientifically proven effects or recommendations. I just experienced how spending my teenage years mostly in the dojo influenced my development. This motivated me to study sports science, mainly so I could be a part of another generation's positive experience during childhood and youth. Through my work, I became involved with a group of children and youth who have trouble participating in leisure activities and even more so organised physical activities and sports – specifically, children and youth with disabilities. Helping this special group to have the same positive experiences as I had in my youth became the motivation for this thesis. Therefore, the aim of this project was the development of a web-based instrument—ActiveYou II—to measure participation in physical leisure activities in the child's home environment. For its first application at Beitostølen Healthsports Center (BHC), Norway, this new instrument is designed to assist in planning and evaluating rehabilitation interventions aimed at increasing participation for children and youth with disabilities.

# 2

## 2. Background

### 2.1 Participation in leisure physical activities for children with disabilities

Children and youth with disabilities often face restrictions on their participation in leisure activities. As a group, these youngsters show lower levels of participation in organised or unorganised leisure activities, especially physical activities, outside the family setting (G. Bedell et al., 2013; M. M. Bedell et al., 2011; Chien et al., 2014; Dolva, Kollstad, & Kleiven, 2017; G. King et al., 2003; M. King, Shields, Imms, Black, & Ardern, 2013; Krieger et al., 2018; Law et al., 2013; Murphy, Carbone, & Disabilities, 2008; Schreuer, Sachs, & Rosenblum, 2014; Shikako-Thomas, Kolehmainen, Ketelaar, Bult, & Law 2014; Solish, Perry, & Minnes, 2010). Based on the positive effects of participation in leisure activities, improving such participation has become one of the most important aims and outcomes of rehabilitation interventions for children and youth with disabilities (B. Adair et al., 2018; G. Bedell et al., 2013; Chien et al., 2014; Cogan & Carlson, 2018; Coster et al., 2011; Hemmingsson & Jonsson, 2005; G. A. King et al., 2006; M. King et al., 2013; Philips, 2013; Sakzekski, Boyd, & Ziviani, 2007; Shikako-Thomas et al., 2014). Every culture has their priorities and tendencies regarding leisure activities. This Ph.D. project is focused on the Norwegian setting, with a culture heavily centered around outdoor and physical activities, as explained in the next chapter.

### 2.2 Participation in physical leisure activities in Norway

According to the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir), physical activity and sports are the most popular leisure activities for children and youth in Norway. Moreover, 77% of Norwegian children aged 1–16 years participate in some form of organised leisure activity (Bufdir, 2018). According to Green et al. (2015), Norwegians show higher levels of participation in leisure activities than children in most other European countries. The Norwegian Helsedirektoratet (2012) reported that 69.8% of nine-year-old girls and 86.2% of nine-year-old boys in Norway follow the WHO's recommendations for physical activity The numbers drop to 43.2% and 58.1% for 15-year-old girls and boys respectively (Helsedirektoratet, 2012).

The WHO (2018a) defined physical activity as 'any bodily movement produced by skeletal muscles that requires energy expenditure'. Furthermore, the WHO defined a moderate level of physical activity as *'requir[ing] a moderate amount of effort and noticeably accelerates the heart rate'* with a metabolic equivalent (MET) between 3 and 6. According to the Centers for Disease Control and Prevention (CDC), this level of activity burns between 3.5 and 7 calories per minute. While participation in physical activities has decreased in other European countries

over the last years – especially for 16–19-year-olds – the numbers in Norway remain stable (Green et al., 2015; Statistics Norway, 2015). In particular, 76% of 6–8 year olds and 87% of 10–15-year-olds participate in physical leisure activities at least once a week. The most popular activities for younger children were football, cycling, swimming and skiing, while older youngsters included going to the gym or health clubs as their favourites (Green et al., 2015). In Norwegian culture, even more importance is placed on enabling children and youth with disabilities to participate in these kinds of activities. This project focused on developing a measure for participation in leisure activities, specifically physical activities during leisure time; thus, this thesis uses the term terminology *physical leisure activities* (see also chapter 2.6). To develop such an instrument, the first step is to define the concept to be measured (Clark & Watson, 1995; Peterson, Peterson, & Gilmore Powell, 2017). Therefore, the concept of participation is described in more detail in the following section.

## 2.3 Participation – A constantly discussed construct

### 2.3.1 Historical perspectives on disability

To understand the construct of participation, one must take a deeper look into the understanding of disability. Throughout history, and depending on the culture, there have been different understandings of disability. For example, Schuelka (2013) explained the ambivalent attitude towards disability in Ancient Greece. The ability to survive disabilities that occurred throughout life (e.g. soldiers wounded in war, disabilities brought by common disease and famine) was seen as a blessing by the gods. This view led to an inclusive society, including laws protecting the rights and properties persons with a disability. In contrast, persons born with disabilities were looked upon as being punished or cursed by the gods, whom their family had displeased. This view led to the widespread practice of infanticide (Schuelka, 2013).

There were several developments within Western, Christian societies (Sastre, 2016) before the creation of the biopsychosocial model of disability promoted by the WHO today (World Health Organisation, 2001) . One of the earliest understandings of disability in Western society is based on religion, specifically the Bible and its interpretations. Such understanding has been called ‘the moral model’ (Kaplan, 2000). Similar to ancient Greece, in both Judaism and Christianity, disability often has been understood as a kind of punishment for sin (Sastre, 2016; Schülein & Reitze, 2016). In the Middle Ages and with Martin Luther’s Reformation, God was no longer responsible for disability; instead, the devil was assumed to possess the person. This shift brought about the notion of disability as curable – mostly through exorcism, devoutness and God’s grace (Schuelka, 2013). Although the moral model is less prevalent

today, it still influences cultural associations of sin and shame with disability for the individual and the family (Kaplan, 2000).

In the modern age, new concepts and models of disability appeared. With the rise of empiricism – in the late 19th and early 20th century – 'the medical model' of disability emerged (Schuelka, 2013). This model explained disability on a physical or biological level (Llewellyn & Hogan, 2000). The main critique on this approach is the denial of environmental effects and influences in creating disability (Hemmingsson & Jonsson, 2005; Llewellyn & Hogan, 2000). (Martin, 2013)In contrast, a constructivist approach – called 'the social model' – evolved in the 1960s and 1970s as a result of the human rights movement (Llewellyn & Hogan, 2000). Here, disability was viewed as a pure construct of society, with the environment creating disability by not adapting to every individual's unique circumstances. The main critique here – even by persons with disability – has been the neglect of the physical and biological origins of disabilities, suggesting that simple adaptation processes in society could erase disability (Sastre, 2016; Swain & French, 2010). To combine the medical and social models of disability, the 'social-relational model' was developed (Martin, 2013). One variation of this model is the biopsychosocial model of participation within the ICF (World Health Organisation, 2001).

### 2.3.2 Participation within the International Classification of Functioning, Disability and Health

When we talk about 'participation' today – at least in healthcare and rehabilitation – it is often in reference to the definition of participation within the ICF – the International Classification of Functioning, Disability and Health (World Health Organisation, 2001). According to the practical manual for the ICF, the ICF is *'a framework for organising and documenting information on functioning and disability'* and *'provides a standard language and conceptual basis for the definition and measurement of disability'* (World Health Organisation, 2013, p. 3). Here, participation is defined as '*involvement in life situations'* (World Health Organisation, 2001, p. 10).

The ICF is the result of a long process implemented by the WHO to develop an international framework. The first classification was the International Classification of Diseases (ICD) published in 1973. According to experts, the ICD gave valuable information about patients with diseases, yet was insufficient in describing the influence of diseases in daily life, which was vital for planning therapy and rehabilitation (Hemmingsson & Jonsson, 2005). Therefore, the ICD was further developed into the International Classification of Impairments, Disabilities and

Handicaps (ICIDH), which was published in 1980. According to Hemmingsson and Jonsson (2005), the ICIDH was the first attempt to classify the consequences of disease.

However, the ICDIH did not consider the role of the physical and social environment. Such factors were first included in the ICF, where participation is a central component, alongside Health condition, Body Functions and Structures, Activities, Environmental Factors and Personal Factors. These components interact with each other, as shown in Figure 1.

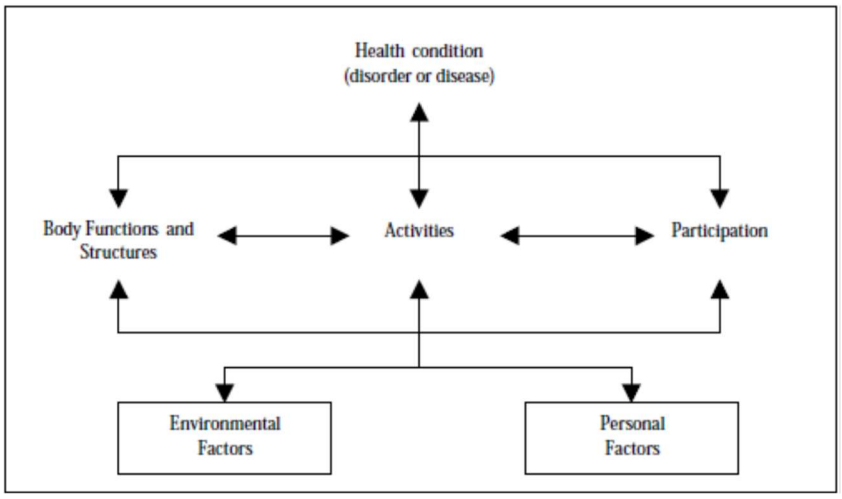


Figure 1: Interactions between the components of ICF (World Health Organisation, 2001, p. 18)

With its introduction of the biopsychosocial model, the ICF was seen as an important step forward in understanding disability (Badley, 2008; Hemmingsson & Jonsson, 2005; Maxwell, Alves, & Granlund, 2012), combining both the medical and social models of disability (World Health Organisation, 2013). The ICF does not generally assume that a person is 'normal' or 'disabled' but instead evaluates the individual level of functioning in a specific setting (World Health Organisation, 2013). However, the ICF was criticised for its lack of individual perspective, and its lack of clarity on the different aspects of participation, and distinction between participation and activities (Badley, 2008; G. Bedell et al., 2013; Coster et al., 2011; Hemmingsson & Jonsson, 2005; Imms et al., 2016; Imms et al., 2017; Maxwell et al., 2012).

Since its publication, multiple authors have tried to improve, adapt or supplement the ICF. Granlund et al. (2012) argued for adding for a third qualifier – in addition to the in the ICF included qualifiers of *'capacity'* and *'performance'* – to capture the subjective perspective of participation.

Rosenbaum and Gorter (2012) adapted the ICF framework and incorporated what they call the five 'F-words' (family, friends, fitness, fun and future) in childhood disability'. They intended a more holistic approach towards childhood disability, distancing themselves from the

traditional focus on 'fixing' and 'normality' and moving towards an approach centred around the individual's strength and abilities. This more holistic approach had considerable impact within research on childhood disability. According to a review by Soper and colleagues (2019), this included research on physical activity and rehabilitation.

Another attempt to supplement the shortcomings of the ICF is the 'Family of Participation-Related Constructs' model (fPRC-model; Imms et al., 2017), which is specifically aimed at supporting children with disabilities in their participation. Here the child is seen within its environment or specific context, with all the individual and environmental factors that influence participation, and how these relate to each other.

Mitra and Shakespeare (2019) argued that the ICF framework has fallen behind the many developments in research and should be revised accordingly. This revision should include a stronger focus on the individual perspective and socioeconomic determinants, as well as how the health conditions themselves are influenced by personal and environmental factors.

### 2.3.3 A pragmatic approach to the participation construct

As one might expect from the critique on the understanding of participation in the ICF, the discussion of the participation construct remains ongoing (Hemmingsson & Jonsson, 2005; Imms et al., 2016; Imms et al., 2017; G. King et al., 2003; Maxwell et al., 2012; Mitra & Shakespeare, 2019; Shikako-Thomas et al., 2014). Even though the ICF works as a starting-pointy of this thesis, this thesis also needs to consider ways to improve the understanding of participation within the ICF.

In their systematic review, Adair and colleagues (2018) argued the importance of having clear definitions of the construct one wants to measure. Furthermore, measure development must keep up with the developments of the participation construct. The ICF lacks clear definitions of subconstructs like involvement and especially the subjective perspective of participation. As the aim of this PhD project is to develop a measure of participation, it is important to find valid definitions for the construct and to include the subjective perspective of participation. Therefore, a more pragmatic approach must be adapted, in which definitions from multiple disciplines are combined into a 'pragmatic' working theory upon which the new instrument can lay. Such working theories are regularly used to measure development when the definition of the measured construct available at the start of the development process is insufficient (Pospeschill, 2010).

Figure 2 shows the understanding of participation at the beginning of this PhD project. The clouds in the figure visualize the uncertainties in the interactions between the parts in the participation construct, which require further research to develop an instrument measuring participation in physical leisure activities for children and youth with disabilities.

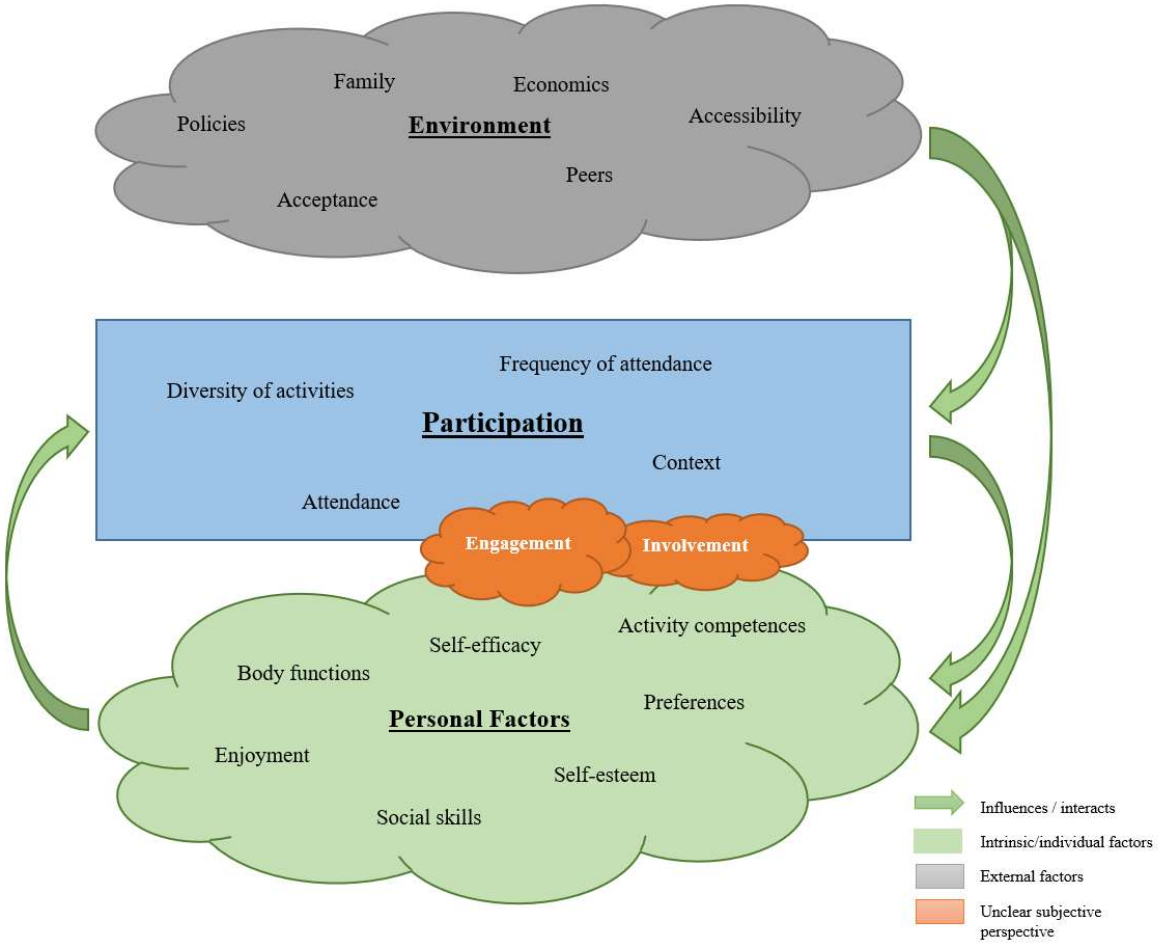


Figure 2: Understanding of 'participation' at the beginning of the research process

### 2.3.4 Why 'pragmatic' – A short interlude

To understand the approach undertaken here, a short introduction to its philosophical background may be useful. The aim of this working theory is to enhance the understanding of participation for children and youth with disabilities. In pragmatism, one does not see knowledge, truth or reality as an absolute – but rather as ideas that constantly evolve (James 1908). When constructing a model or theory, the aim is to find the 'right' language to further understand and better cope with the world (Hellmann 2009). This process is always grounded in doubt or conflict with the current state of knowledge (James 1908; Schubert, 2010).

In this sense, the work on the participation construct in this thesis is grounded in the ongoing discussion and missing clarity of different aspects of the participation construct – the starting

doubt. In the research process, one should be open to all theories that might make a practical difference (James 1908). Following this maxim, it makes sense to include disciplines in one's research that may not be immediately at hand. As explained later, research in this thesis, therefore, examined other research fields—aside from rehabilitation—to identify sufficient definitions for parts of the participation construct, which are presently lacking.

## 2.4 Incorporating the child's perspective into research

William James (1908), a founder of the philosophical school of pragmatism, noted that one can never understand another person's reality completely but can only try one's best to empathise with the opponent's position. Therefore, to understand the position of children and youth with disabilities with regards to their participation in leisure activities and sports, the most valid source of data are the children and youth themselves. This is in line with the United Nations Convention on the Rights of the Child (UNCRC), which provides in article 12 that it is important to

> *[…] assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child […].* (Unicef, 1989, p. 5)

Additionally, the Convention on the Rights of Persons with Disabilities provides in article 7 that on the matter of hearing the children's voice

> *States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.* (United Nations, 2006, p. 8)

Both of these international declarations demand incorporating the voice of children, according to their abilities, on matters that affect them. In a focus group study, Hammel et al. (2008) found that their participants with a variety disabilities did not *'want people to make assumptions about their needs; they wanted to be recognized as the experts regarding their needs, and wanted to be consulted…'* (Hammel et al., 2008, p. 1452). In line with this notion, researchers studying children and youth with disabilities have put an increased focus on including children in their studies (Andersen & Dolva, 2015; Baksjøberget, Nyquist, Moser, & Jahnsen, 2016; Cuskelly, 2005; Hedegaard & Fleer, 2008; A Nyquist, Moser, & Jahnsen, 2016; West, Hauser, & Scanlan,

1998; C. Willis, Nyquist, Jahnsen, Elliott, & Ullenhag, 2018; C. Willis et al., 2017; C. Willis, Reid, et al., 2018).

### 2.5 The need for Norwegian Instruments on adapted physical activity in a rehabilitation context

To evaluate the effect of interventions designed to enhance participation in (physical) leisure activities, research and intervention providers need valid measures (B. Adair, Ullenhag, Keen, Granlund, & Imms, 2015; Babulal et al., 2015; Chien et al., 2014; Coster & Khetani, 2008; Coster et al., 2012; G. King et al., 2004; M. King et al., 2013; Philips, 2013; Sakzekski et al., 2007). However, especially for the Norwegian setting, such a measure is still missing. There have been previous efforts to undertake cultural validation of existing international instruments, like the Preferences for Activities of Children (PAC) and the Children's Assessment of Participation and Enjoyment (CAPE; (Hoberg & Nyquist, 2011; Nordtorp, Nyquist, Jahnsen, Moser, & Strand, 2013). Hoberg and Nyquist (2011) conclude in their report that there are specifics to the Norwegian setting and its variety of activities that cannot be captured using PAC and CAPE. In addition, they report difficulties in administering the questionnaires, especially with children and youth with learning disabilities. As well, participants expressed their wish for a digital questionnaire that they can administer using the computer, tablet or smartphone. Furthermore, there have been issues publishing the Norwegian version of PAC and CAPE. Pearson declined to publish the Norwegian version because Norway is a very small market (Dalen et al., 2020; Nordtorp et al., 2013).

Coster and colleagues (Coster et al., 2011; Coster et al., 2012) developed the web-based Participation and Environmental Measure for Children and Youth (PEM-CY). This instrument is designed to serve children with various physical, mental and/or emotional disabilities. The child's parents administer it. Besides traditional variables like frequency and setting, this instrument also included factors that facilitate and hinder participation. However, PEM-CY is an instrument administered by parents and therefore does not fit the intention to hear the child's voice directly.

To meet this challenge, the development of ActiveYou I (Dalen, 2019; Dalen et al., 2020) and ActiveYou II was initiated by Beitostølen Healthsports Center (BHC), inspired by PAC and CAPE. BHC is a rehabilitation center within the Norwegian specialist healthcare system and a provider of interventions based on adapted physical activity for children and youth aged five to 17 years, with different disabilities and chronic diseases. The aim of rehabilitation at BHC is to increase activity and participation throughout life, especially physical activities in the individual's local environment (Nyquist, 2012). The instruments are designed to focus on

physical activities the individuals would like or already participate in (Dalen et al., 2020). ActiveYou I is an instrument—similar to PAC—that measures the individuals' activity preferences during their rehabilitation intervention (Dalen et al., 2020), and adjusts the rehabilitation intervention to the individual needs of every client. ActiveYou II, on the other hand, aims to evaluate the effect of the intervention. In other words, ActiveYou II assesses whether there is a change in the participation pattern, involvement, or hindering and facilitating factors for participation after the intervention. Therefore, clients are expected to fill out the ActiveYou II before they start the intervention, and 3 months post intervention to see if there has been a change in any of the participation dimensions (see also figure 3). Both ActiveYou I and ActiveYou II are designed to be generic instruments. Apart from their first application at BHC, which will focus on physical activities, applying the instrument in other settings comes with the possibility of varying the set of activities according to individual needs.

### 2.6 The context of the development of ActiveYou I and II: Beitostølen Healthsport Center

As a rehabilitation service provider for children and youth with disabilities, BHC is the first applicant for the new instruments. One of their therapy models for children and youth is called the 'Local Environment Model' (A Nyquist, Jahnsen, Moser, & Ullenhag, 2019; C. Willis et al., 2017) for children and youth from age five to 17 with any disability. This model is family-centered and focuses on collaborating with local educators and healthcare service providers (Nyquist et al., 2019). The main goal of the intervention is to facilitate participation in the children's home environment. The process of the intervention within the 'Local Environment Model' is shown in figure 3. ActiveYou I and ActiveYou II are supposed to facilitate the planning process for the intervention, by mapping the children's activity preferences for their stay at BHC (ActiveYou I), their participation pattern in their home environment, and the facilitators and barriers to participation (ActiveYou II). ActiveYou II is also expected to capture possible changes in the children's participation after their 3-week stay at BHC. Therefore, the instruments focus on activities the clients perform in their home environment or desire to participate in.

ActiveYou II is developed in a specific context and in close connection to the rehabilitation program of children and youth aged 5 to 17, with a large variety of disabilities; thus, the target group for the new instrument was pre-set before the beginning of the project. Furthermore, within the setting of BHC, the main focus lies on physical activities. Therefore, the instrument mainly includes physical activities the children participate in during their leisure time.

However, as mentioned above, the activities and pictures may be changed according to the needs of other contexts (see Appendix 4B).

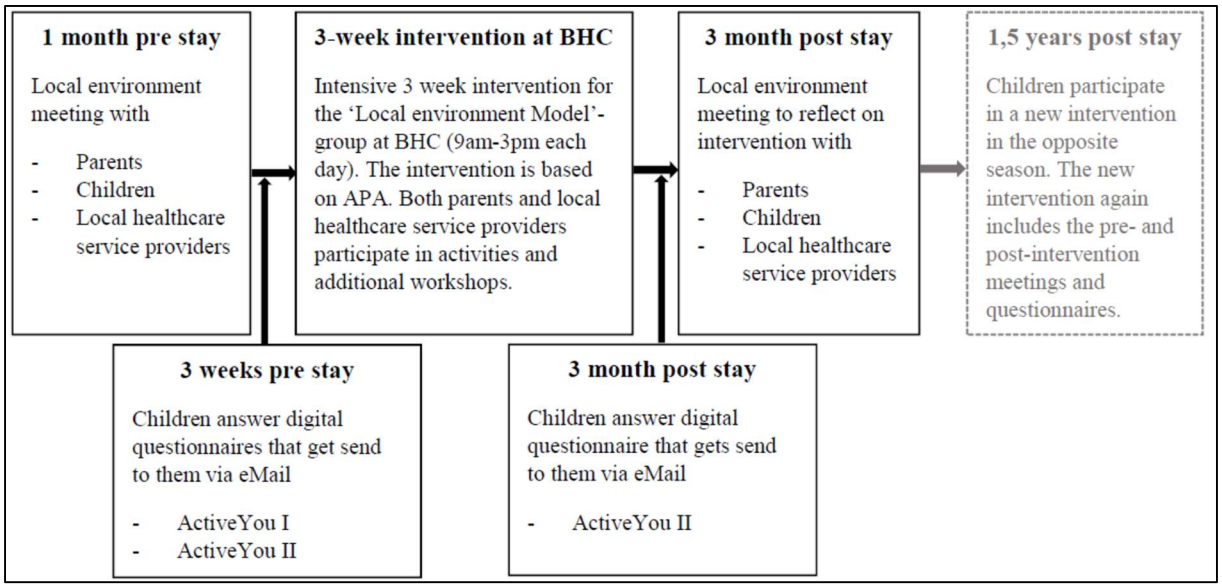


Figure 3: Local Environment Model at BHC

## 2.7 Aim of this project

As described above, there is a lack of self-reported, web-based instruments that evaluate the participation in physical leisure activities for children and youth with disabilities in Norway – which are needed to plan and evaluate interventions aiming towards increasing participation – this research project aims to develop such an instrument.

As a result, the development of ActiveYou I and ActiveYou II were initiated, as described above. This PhD project is dedicated to the development process of ActiveYou II. This new measure is aimed at measuring participation patterns in different physical leisure activities of children and youth with disabilities in their home environment. Therefore, the main research-aim of this project is to:

> Develop a web-based, self-reported instrument for participation in physical leisure activities for children and youth with disabilities, adjusted to the Norwegian setting.

Initially, the instruments were called BARNAS I (now ActiveYou I) and BARNAS II (now ActiveYou II), which later have been changed to AktivDeg I and AktivDeg II. Therefore, some information letters found in the appendix still have the name BARNAS II or use the Norwegian AktivDeg II. As this thesis is written in English, it will use the English name of the instrument.

## 2.8 Research questions

The aim of the project leads the researcher to pose several research questions.

First, to measure something, clear definitions of the construct at hand are needed (B. Adair et al., 2018; Andrews, Durvasula, & Akher, 1990; Barki & Hartwick, 1989; Himmelfarb, 1975; G. King, Currie, & Peterson, 2014; M. King et al., 2013; Zaichkowsky, 1985). Furthermore – as described above – the participation construct remains under constant discussion and further development (B. Adair et al., 2018; Babulal et al., 2015; Hemmingsson & Jonsson, 2005; Imms et al., 2017; G. King et al., 2003; Maxwell et al., 2012; Mitra & Shakespeare, 2019; Shikako-Thomas et al., 2014). In their systematic review on measures for participation, Adair and colleagues (2018) discussed how measurement development must keep up with the development of the construct. Therefore, it is important for this project to take a deeper look at the participation construct.

Here, in the field of rehabilitation there is a knowledge gap regarding the subjective dimensions of participation, involvement and engagement (B. Adair et al., 2018; Imms et al., 2016; Imms et al., 2017). Therefore, Article 1 poses and discusses the following research question:

> Are there definitions for the constructs of 'involvement' and 'engagement' suitable for measurement development in other fields of research, which can be transferred to healthcare and rehabilitation?

Second, every setting has its own specifics that warrant consideration when developing a valid and reliable instrument (Arvidsson et al., 2019; Coster et al., 2012; Hoberg & Nyquist, 2011; Law et al., 2013). Therefore, it is important to research specifics relating to the Norwegian setting. Ullenhag et al. (2012) discussed, for example, how different policies or support from the welfare system can influence participation in Norway, Sweden and the Netherlands. Several international studies have investigated barriers for participation in leisure activities (Krieger et al., 2018; Rimmer, Riley, Wang, Rausworth, & Jurkowski, 2004; Shields & Synnot, 2016; Shields, Synnot, & Barr, 2012). Some of these studies have pointed out that beyond just researching barriers for participation, research and rehabilitation service providers should also focus on the potential of facilitators (Rimmer et al., 2004; Shields et al., 2012). Coster and colleagues (2012) decided to include facilitating and hindering factors in their instrument PEM-CY. These factors may vary internationally.

Therefore, it is important to identify facilitators and barriers specific to the Norwegian setting. Because ActiveYou II is designed to be a generic instrument, with the option of changing the sample of activities; it was important to study these facilitators and barriers for leisure activities and not just the physical activities. The second article discusses the following research question:

> What kind of facilitators and barriers for participation in leisure activities do children and youth with disabilities and their families experience in Norway?

Third, before applying a new instrument in practice, it is important to test the instrument for item quality and psychometric properties. The third article discusses the item quality of ActiveYou II using cognitive interviews and poses the following research question:

> Can cognitive interviews with children and youth help to improve item quality of ActiveYou II?

Based on the results of these three articles – and additional work that will be described in more detail in this thesis – the development process of ActiveYou II will be summarised and discussed.

## 2.9 Structure of this thesis

This thesis is organised as follows. Chapter 1 introduces the thesis. Chapter 2 presents the background of the research. Chapter 3 discusses the methodology used during the research for this thesis, which included scoping reviews as a method for structured literature research and different interview technics. Furthermore, a description of the recruitment and data collection in the different parts of the study is given along with the ethical considerations.

Chapter 4 explains the results of the research, which are based primarily on the three articles. These articles are discussed in relation to the overarching aim of the thesis. Chapter 5 provides a general reflection on the project as well as its strengths and limitations. Chapter 6 concludes the thesis.

## 2.10 Process of instrument development

According to Moosbrugger and Kelava (2012), tests and measures work on the assumption that we can describe a person based on his/her individual properties, which relate to a concrete construct – as is the case of ActiveYou II participation. The development of such an instrument is based on a multistage process (Moosbrugger & Kelava, 2012; Pospeschill, 2010). The first step is to determine what construct needs to be measured and if sufficient theories/models are available (Moosbrugger & Kelava, 2012). Even though the ICF presents an international framework that includes the concept of participation, this framework may not be sufficient for the development of ActiveYou II. Pospeschill (2010) argued that in such a case, a working model should be developed throughout the research process – as done in this thesis. To clarify

the construct, a more in-depth literature research is needed (Moosbrugger & Kelava, 2012; Pospeschill, 2010).

After clarifying, construct decisions on item development are needed. Such decisions are affected by whether the construct is uni- or multidimensional, if it is stabile over time and if the measured properties are nominal or ordinal nature (Moosbrugger & Kelava, 2012; Pospeschill, 2010). As described earlier, participation is a multidimensional construct. The target population influences further item development, such as the general layout of the instrument, test length (number of items), duration (time needed to administer the test) and types of items (Moosbrugger & Kelava, 2012; Pospeschill, 2010). To incorporate the target group into the development of ActiveYou II, group interviews were included in the research process (article 2), as well es cognitive interviews in order to test a first version of the instrument (article 3). Furthermore, the instrument needs to be tested with an analysis sample similar to the target group (Moosbrugger & Kelava, 2012; Pospeschill, 2010). In this thesis, testing – using cognitive interviews– with the target group were executed, as represented in article 3.

The process of developing ActiveYou II is illustrated in Figure 4. Such process includes past research on the cultural validation of PAC and CAPE in Norway (Hoberg & Nyquist, 2011; Nordtorp et al., 2013), which led to the development of the instrument and future directions, and further research (e.g. psychometric properties of the new instrument) that went beyond the capacities of this PhD thesis. In this regard, the literature research and article 1 build a theoretical foundation regarding the participation construct. More specifically, the subjective aspects of participation 'involvement' and 'engagement' is discussed as a contribution to fill a knowledge gap where these dimensions have often been missing in measures thus far. Article 2 investigates peculiarities to the Norwegian setting regarding the facilitating and hindering factors for participation in leisure activities. Together, these two articles build a basis for the draft of the first version of ActiveYou II, which then was tested using cognitive interviews (article 3).

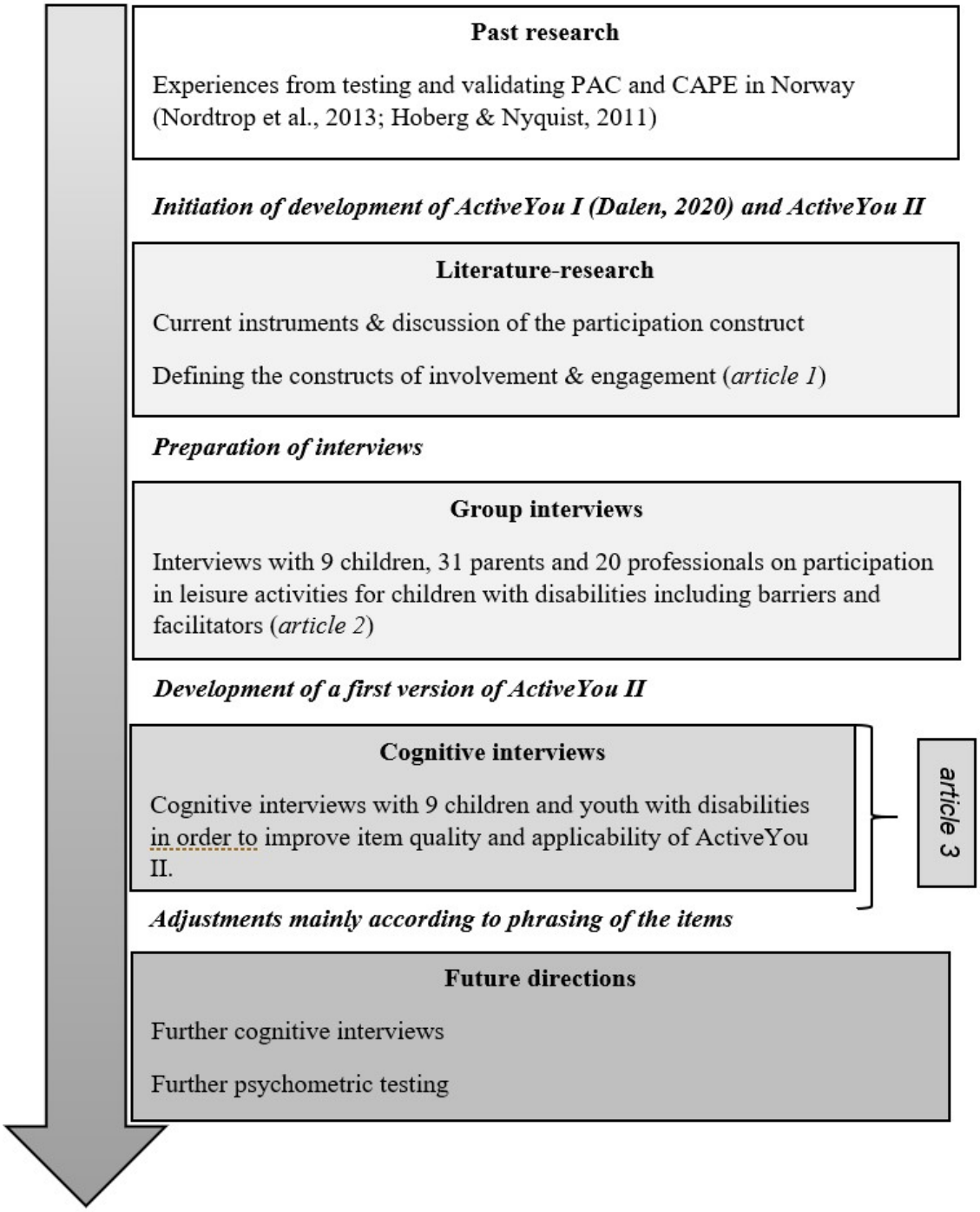


Figure 4: Flow chart describing the research process for this thesis

# 3

## 3. Research methods

This project adopted different methods. Both qualitative interview methods and a structured literature review were used to answer the research questions. As explained in Chapter 2.4, this thesis promotes the importance of incorporating the perspective of children and youth with disabilities. The ICF practical manual argues that persons with disabilities *'can provide direct information in an interview, through a questionnaire, or through other forms of self-reporting'* (World Health Organisation, 2013, p. 15). The methods used in this thesis were a structured literature research (a scoping review), group interviews and cognitive interviews with the new ActiveYou II under development.

This chapter explains why these methods were chosen, including special considerations, especially involving interviews with children or developing questionnaires for children (with disabilities). Table 1 gives an overview of the different research methods applied during the project and their aims.

Table 1: Research methods applied during the research

| Article or study title | Method used | Research aim |
|---|---|---|
| 1 | Scoping review | Find valid definitions for the participation sub-constructs of involvement and engagement |
| 2 | Group interviews | Identify facilitating and hindering factors for participation in leisure activities for children and youth in Norway |
| 3 | Cognitive interviews | Test the first version of ActiveYou II for item quality and applicability |

### 3.1 Structured literature research using scoping reviews

A structured literature review was not originally part of this project. However, during an early phase, when basic literature research on the participation concept was done, it became apparent that several parts within the participation construct seemed unclear. Discussions with experienced researchers and further literary work made it clear that one cannot possibly measure a construct without having concrete definitions of the constructs to be measured (B. Adair et al., 2018; Andrews et al., 1990; Barki & Hartwick, 1989; Himmelfarb, 1975; G. King et al., 2014; Zaichkowsky, 1985). This is especially true for subjective subdimensions of

participation – involvement and engagement – which to date have often been neglected in measures (B. Adair et al., 2018). However, scholars see a necessity of including the subjective perspective when measuring participation (B. Adair et al., 2018; Babulal et al., 2015; Coster & Khetani, 2008; Granlund et al., 2012). Therefore, it was important to find more clear definitions for these subjective aspects of participation to measure them. This challenge called for a more structured approach in the literature research, which led to the first article included in this thesis.

There are many forms of structured literature research, with the most known possibly being the systematic review or meta-analyses. According to Arksey and O'Malley (2005), the main difference between a systematic and a scoping review is that the former is based on one well-defined question with a quite narrow scope, while the latter often has a broader topic. As the task in this project was to examine several quite broad concepts that seemed unclear, the research question for the review also needed to be quite broad and open. Therefore, a scoping review seemed to be the most feasible method. There are four reasons for using the scoping review method (Arksey & O'Malley, 2005): (1) to examine the extent or range or of research activity in one field; (2) to determine the value of a full systematic review; (3) to summarise/disseminate research findings; and (4) to identify research gaps. For this thesis, it seemed clear that there was a research gap. The approach was to summarise ideas and findings in other fields of research that might be adapted into the field of disability research or healthcare and rehabilitation. This is closest to the third reason for using the scoping review method, as noted above.

As scoping reviews are a relatively new variant of literature research, guidelines that have been established for systematic reviews for a long time were not available for scoping reviews at the beginning of the project (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brian, 2010). More recently, the PRISMA-ScR guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) were published as a general guideline for authors to follow while using the method (Tricco et al., 2018). PRISMA-ScR provides a framework for the process of the review process, including (Tricco et al., 2018):

- Report the chosen method in the title
- Provide a structured summary
- Describe the rationale and objective of the review
- Report existing review protocols, sources of evidence, databases used, search strategy, inclusion and exclusion criteria, data charting and condensation of data

- Give an overview of the number of sources screened and the screening process (ideally in flow diagram)
- Report results from each individual source of evidence
- Summarize the results and relate them to research questions, objectives and existing research
- Discuss the limitations of the research process
- Provide a general interpretation of the results and implications for future research
- Report sources of funding and the role of the funders of the scoping review

Today, most journals require authors to submit a completed PRISMA-ScR checklist when submitting a scoping review. Therefore, the scoping review performed in this thesis also applied the PRISMA-ScR guidelines/checklist. In this project, to target definitions of the constructs of involvement and engagement, the databases shown in Table 2 were included in the research. These databases were chosen through a discussion with experienced researchers in the field of literature -studies. It was expected that the research would cover the most relevant fields and publications.

Table 2: Databases included in the Scoping review on involvement and engagement

| | |
|---|---|
| **Involvement** | |
| Healthcare and rehabilitation | MEDLINE; PubMed |
| Leisure research | Academic Search Complete; PsychINFO |
| **Engagement** | |
| Healthcare and rehabilitation | MEDLINE; PubMed |
| Educational psychology | Academic Search Complete; PsychINFO |
| Human resource management | Business Source Complete |

After screening titles and abstracts, relevant full texts were analysed. In addition, snowball search was applied to catch important publications that were missed in the research due to keywords or filters.

### 3.2 Considerations when interviewing children (with disabilities)

A considerable part of this thesis consisted of data collection with various forms of interviews. Group interviews were used at the beginning of the developmental process of ActiveYou II. This interview method helped to identify facilitators for and barriers to participation in the

Norwegian setting (see also article 2) and a more general perspective of parents, children and professionals on participation in leisure activities. Later, cognitive interviews were used to improve the item quality and applicability of ActiveYou II. As this project concerns the participation of children and youth with disabilities, it was essential to include those among the group of informants.

However, there were several issues to consider when interviewing children, especially children with disabilities (Docherty & Sandelowski, 1999; Finley & Lyons, 2001; Heath, Brooks, Cleaver, & Ireland, 2009; Lewis & Porter, 2004). Lewis and Porter (2004) developed guidelines for interviewing children and youth with disabilities. They contain several questions the researcher should address during the research-process. These guidelines were used during the interviews in this project. A summary of the guidelines for interviewing children with learning disabilities can be viewed in Table 3.

Table 3: Guidelines for interviewing children with learning disabilities (Lewis & Porter, 2004)

| **Part of the research** | **Questions to consider** |
|---|---|
| Research Aims | • Will the research be useful to/relevant for the lives of persons with disabilities?<br>• Have persons with disabilities contributed in establishing the aims or purpose of the research?<br>• Can the research possibly be harmful for the persons involved? |
| Access / Gatekeepers | • How can participants be contacted (e.g. locations, institutions)?<br>• How can the involvement of multiple players/agencies facilitate or hinder the research?<br>• Are the views of participants represented by the gatekeepers or proxies? |
| Consent / Assent | • Are participants fully informed to give consent?<br>• Are participants capable of giving full consent?<br>• If third parties give consent for participants, did the participants give assent?<br>• Is consent/assent checked for throughout the research process?<br>• Have the participants been informed about the confidentiality and anonymity of the data? |
| Confidentiality / Anonymity / Secrecy | • Can the confidentiality of all parties be guaranteed?<br>• Is anonymity guaranteed in all cases?<br>• How can confidentiality and anonymity be guaranteed and sustained throughout the research process? |
| Recognition / Feedback / Ownership | • Are participants rewarded for their involvement in the research – and how?<br>• Have participants adequate chances to give feedback?<br>• How can participants contact the researcher(s)?<br>• Is the end of the research process/involvement clearly communicated to the participants? |

| | |
|---|---|
| Social Responsibility | • Does the research follow all social, moral and legal responsibilities? |
| Sampling | • Is there adequate heterogeneity in the sample with regards to diagnosis, demographics or socioeconomic factors?<br>• Is there awareness of communication needs and their possible impact on researcher requirements/sampling (e.g. resigning capabilities/ICT skills and access)?<br>• What are strategies to adapt the research to the different cognitive levels of the participants? |
| Design | • Are research questions and aims communicated clearly?<br>• How is the relationship with participants built over time?<br>• What are the benefits for individual participants and for the general population?<br>• Are (and how) is the target population involved in the research design? |
| Communication | • Are interview guides adjusted to the target population?<br>• How can individuals with limited communication abilities participate in the research?<br>• How can interview situations be facilitated by the use of multimedia, cue cards, etc.? |

### 3.2.1 Group interviews

For this thesis, it was important to get an insight into the individual perspective of children with disabilities, parents and healthcare professionals. It was important to identify facilitators for and barriers to participation specific to the Norwegian setting and the participants' perception of their participation and of participation (as a construct) in general. According to Frey and Fontana (1991), group interviews are useful to satisfy the researcher's curiosity and attain a better understanding of a social construct. McLafferty (2004) further argues that group interviews enable the researcher to have a source of data based on participant interaction because they can enhance the development of questionnaires. These are arguments that facilitated the decision to include group interviews in the developmental process of ActiveYou II.

Furthermore, research on the development of other instruments – specifically the PEM-CY – used group interviews during the development of their instrument (Coster et al., 2012). For the development of the PEM-CY, the researchers interviewed both parents and healthcare professionals about their perspective of participation as well as about hindering and facilitating factors. However, as explained earlier, there has been an increased focus on incorporating the child's perspective into research. Furthermore, the PEM-CY is an instrument that is meant to be administered by the parents of the child, while ActiveYou II is intended to be a self-reported instrument, where the child – with parental assistance if needed – responds. Therefore, it was

seen to be especially important to incorporate the perspectives of children and youth as direct informants into the study.

Three specific groups – parents, healthcare professionals and children – took part in the interview-process, and the interview guide needed to be adjusted for them. An English translation of the interview guide can be found in article 2. Regarding sample size, McLafferty (2004) differentiates between full groups with 10–12 participants and mini groups with four to five participants. She also provides pros and cons for both variants, noting that mini groups are more labour intensive because more interviews are needed to reach an appropriate number of participants and saturation. However, mini groups tend to be easier to manage, and there is a higher chance that all participants will be able to be active in the interview situation.

For these reasons, and especially to give the children a more intimate atmosphere, mini groups were used. Inclusion criteria for interviews were:

- For all groups:
    - Consent for participation
    - Ability to participate in an interview in Norwegian
- Children:
    - Consent by both caregiver and children
    - Age 7–17 years old
    - Being identified with some kind of disability
- Parents
    - Consent from both parents and consent/assent from children with disability
    - Caregiver for a child with some kind of disability
- Professionals:
    - Experience of at least one year in working with children with disabilities

The number of interviews was decided primarily by the point of saturation. When there were no new themes appearing in the interviews with one group (parents, professionals or children), one more interview was conducted before finalizing the interview period for this group.

### 3.2.2 Cognitive interviews

Cognitive interviews are another interview variant specifically used in instrument development. The method has proven to improve item quality and applicability of new instruments (Moosbrugger & Kelava, 2012; Peterson et al., 2017; Spencer, Bouffard, & Watkinson, 2020; G. B. Willis, 1999, 2015). When conducting cognitive interviews, the researcher goes through

the instrument with the participants, who articulate their thoughts while reading and answering the questions.

Peterson and colleagues (2017) describe two strategies for this method – think aloud and verbal probes. When following the think aloud strategy the interviewees freely express their thoughts and ideas while going through the instrument. Here, the researcher adopts more of a passive and observant role. This variant has the ability not only to catch aspects the researcher has considered beforehand but also to bring in new perspectives on the instrument, including possible weaknesses not considered.

However, the 'think aloud' variant of cognitive interviews needs some practice beforehand and a high cognitive level of the participants (Peterson et al., 2017). As children were the respondents in this study, Spencer, Bouffard & Watkinson (2020) argue that the 'verbal probe' method should be preferred. Therefore, this study used the 'verbal probe' method. Here, the researcher has a more active role in leading the participants through the instrument, following a previously developed interview guide (Peterson et al., 2017). The interview guide focused on specific formulations (verbal probes) or mechanics of the instrument, which might be challenging or difficult for the participants. Peterson et al. (2017) recommend 5–15 interviewees.

### 3.3 Considerations regarding the use of survey methods with children (with disabilities)

This thesis aimed to develop a new instrument based on a child-reported questionnaire; thus, it was important to consider issues connected to the use of such methods with children. Applying surveys to groups of children, and especially to children with disabilities, poses several challenges. Heath and colleagues (2009) present a general overview on what to expect, and what to consider, when including children of different ages:

- 4–7 years:
    - Short attention span
    - Limited language skills/reading skills
    - ➔ Surveys should be guided and short and composed of simple questions
- 8–11 years:
    - More developed language skills
    - Ability to distinguish between different points of view
    - ➔ Ability to answer simple self-administered questionnaires with attractive and focused questions

- 12–16 years:
    - Well-developed cognitive function
    - ➔ Ability to complete standardised questionnaires as with adults but use appropriate language

Furthermore, Heath and colleagues (2009) see many opportunities in online surveys, with the internet being a natural feature of young people's lives nowadays.

According to Finley and Lyons (2001), instruments developed for the general public often have shown to be inappropriate for children with disabilities. During research on PAC and CAPE in Norway, it has been shown that even if these instruments were developed for children with physical disabilities, they appear to present challenges when applied with children with cognitive or learning disabilities (Hoberg & Nyquist, 2011). Finley and Lyons (2001) offer several points to consider when designing questionnaires for children with cognitive or developmental disabilities, including:

- Avoid Likert-type scales
- Check phrasing and understanding of questions and answers
- Avoid negative wording/phrasing
- Avoid modifiers, particularly at the end of sentences
- Avoid passive phrasing
- Ask specific rather than general questions
- Check the design of the instrument beforehand

Based on the formulation and understanding of issues, this project chose to test a first version of ActiveYou II using cognitive interviews, as described earlier. I regards to Likert-type scales, Read and Fine (2005) researched various alternatives in questionnaires for children and found that smileys work best, especially with young children. Another alternative would be the use of the visual analogue scale (VAS). Von Baeyer (2006) argues, in a study on pain experience, that children prefer face scales (pictures of facial expressions that show different stages of pain) over VAS. In his study, VAS gave valid results, starting at the age of seven. Funke, Reips and Thomas (2011) have found that slider scales (a variant of VAS) show higher response times and break-off rates, especially for participants with a lower educational level. Therefore, smileys were chosen when developing ActiveYou II. Not least because most of the children and their families already have experience from several surveys and questionnaires – within the

healthcare system, education or related to research – prioritising smileys over other alternatives should be double-checked during group interviews and cognitive interviews.

### 3.4 ActiveYou II

As mentioned in Chapter 2, the development of ActiveYou I and ActiveYou II resides in the experiences made while testing the Norwegian versions of the PAC and CAPE instruments for its psychometric properties (Nordtorp et al., 2013). ActiveYou I – similar to PAC – focuses on the activity preferences of children (Dalen, 2019). ActiveYou II focuses on the participation patterns in leisure physical activities among children and youth in their local environment. However, experience with CAPE has shown several aspects that needed consideration for the home environment, as reported by Hoberg and Nyquist (2011). These aspects included that the sample of activities in PAC and CAPE did not seem optimal; they lacked facilitating and hindering factors and had difficulties applying the paper forms.

These shortcomings enhanced the need for an instrument that can be administered on the internet, incorporates facilitating and hindering factors for participation, and includes a sample of activities fitting for the Norwegian setting. Furthermore, with the focus on the individual perspective, these aspects of participation should be included as well. Therefore, in the early stages of the development, it was decided that the following aspects of participation should be covered:

- Frequency of Participation:
    - How often does the individual participate?
    - Is the individual satisfied with his/her frequency of participation?
- Setting:
    - With whom or where does the individual participate in the activity?
    - Is the individual satisfied with the setting?
- Level of Involvement/Attraction:
    - How important is the activity for the individual?
    - How much is the individual attracted to the activity?
- Sense of Mastery:
    - How well does the individual master the activity?
- Facilitating factors:
    - What helps the individual to participate?
- Hindering factors/Barriers:

- What, if anything, hinders the individual from participating in the activity in the way they would like?

Many children participate in a variety of activities in various settings. For example, one might play football both unorganised with their friends and organised at a football club. Research on the constructs of involvement and engagement has shown that *involvement* describes the general interest towards an activity, while *engagement* is context-specific (see also Article 1). In the latter case, an instrument would need to measure the level of engagement for each setting in which the child participates. Therefore, it did not seem feasible to include the level of engagement in the instrument. This decision was made for reasons of practicality, as it would have been difficult to programme this option, and time, as this would have extended substantially the time needed to answer the questionnaire. A more detailed description of how the first version of ActiveYou II was constructed is given in chapter 4.3.

### 3.5 Recruitment and data collection

This project was done in close cooperation with Beitostølen Healthsports Center in Beitostølen, Norway (see also chapter 2.6).

Altogether about 400 children and youth between five and 17 years of age attend a three-week intervention each year. This range meant the project could have a broad cohort of potential participants to recruit from, in terms of diagnosis, urban and rural areas, and other sociodemographic variables. Furthermore, it was beneficial to have insight into the setting and the (daily) routines of the clinic (the PhD student has worked at the clinic for several years, see also chapter 3.7) to coordinate different aspects of the project and have close contact with the therapy team, as the main gatekeepers.

The recruitment process for the different parts of the project is described in the second and third articles. Information letters and consent forms can be found in the appendix of this thesis. The recruitment and data collection process for group interviews took place over a four-month period. In this period, ten different groups with approximately 90 children altogether and their parents were invited to participate in the project. The recruitment for cognitive interviews was especially assisted by another researcher (Lars Kristian Dalen; as mentioned in Appendix A4), how participated in the information-meetings with the children groups. For cognitive interviews, recruitment included three children's groups at BHC with 25 children altogether. Further details on the recruitment process are given in articles 2 and 3.

### 3.6 Ethical consideration

The project has been approved by the Norwegian Centre for Research Data (reference number 52305/3/STM). From the beginning, it was clear that when one conducts research with children and youth with disabilities, the main informants would be part of a vulnerable group. This fact needed to be considered within recruitment, data collection, and analysis and reporting of the data. Most of these aspects have been identified in Table 3. During recruitment, both children and parents were informed about all parts of the project, so they could decide together. Furthermore, contact information was included in the information letters and questionnaire, so the participants could reach the researcher at any given point. For interviews with parents, it was requested that the children give their own consent because they would be the main topic of the interviews in some way. During the analysis and reporting of the results, much attention was given to the anonymity of the children. Participants' names were anonymized and replaced with fictional names in the results. Furthermore, details in quotes that might lead to identification of individual informants in articles or this thesis were changed.

### 3.7 Considerations regarding the researcher's position/connection in the research context

I worked at BHC before starting this Ph.D. project; thus, it is important to reflect on my connection to the research setting. Because of my close connection to the setting, I quit my employment relationship with BHC—rather than a leave of absence for the PhD period—when I started working on the thesis, to avoid bias. However, my connection to the research setting came with both advantages and disadvantages. On the one hand, my knowledge of the research setting facilitated the communication between me as the researcher and the gatekeepers at BHC. Furthermore, I was able to work closely with the researchers at the research section of BHC. For example, Lars Kristian Dalen (nurse, master student, and head of the Rehabilitation department)—who led the development of ActiveYou I—assisted during the recruitment of participants for cognitive interviews (see Appendix A4). Knowing the daily schedule of rehabilitation facilitated the coordination of the project. In addition, being familiar with the intervention activities enhanced the possibility of building relationships with the potential participants of the project and organizing the data collection (i.e., information meetings or interviews) around the daily schedule of the participants. This again facilitated and shortened the communication with the staff.

On the other hand, being so familiar with the research setting and intervention came with a risk of being biased. Therefore, as a former employee, it was important to take on a new role as a researcher and establish a new relationship with the research setting. There was a risk of

interpreting data based on one's own experiences. I incorporated different groups of participants besides the group of healthcare professionals within my professional background to help minimize this risk of bias.

## 3.8 Analysis

This thesis adopted an approach that combined different interview-methods and a structured literature review, so the analysis process varied across different parts of the project.

For the scoping review, the analysis followed the framework of Arksey and O'Malley (2005) and the PRISMA-ScR guidelines (Tricco et al., 2018). After screening databases for articles and snowball research, publications were analysed and information relevant to the research questions was extracted as follows:

- Author and year of publication
- Type of study
- Definition of involvement or engagement
- Important results / information about involvement or engagement
    - Subdimensions
    - Measures used or developed

After the first phase of review, these data were further reduced and prepared for reporting.

Data from the group and cognitive interviews were analysed using qualitative content analysis (Elo et al., 2014). The analysis process was conducted using MAXQDA 2018 software (Verbi, 2018). First, data from the group interviews were prepared for analysis by transcribing the interviews and reading through the transcripts several times. Thereafter, a first round of coding was done using the questions of the interview guide as main categories. This was followed by an inductive analysis, with open category building.

During the inductive analysis process for the group interviews, categories similar to the conceptual model of factors affecting the recreation and leisure participation of children with disabilities appeared (G. King et al., 2003). To facilitate reporting the results and communication within the field of healthcare and rehabilitation, the model was adapted for a more deductive round of analysis. Hereafter, the information from the data was charted as follows:

- Category / conceptual theme
- Information from the interviews

- Exemplary quotes

These charted data formed the foundation for reporting the results.

The cognitive interviews were also processed using qualitative content analysis and MAXQDA 2018 software. Coding took place directly in the audio data. The analysis followed Tourangeau's (1984) question and answer model, with the main categories as follows:

- Comprehension
- Retrieval
- Judgement
- Response

Quantitative data were analysed with support of SPSS version 25 software.

# 4

# 4. Results

This chapter presents the results of the project. First, there is a summary of the three articles included in the thesis. In addition to the results specific to the articles, these will also be discussed in relation to the understanding of participation and their influence on the instrument development. In a separate chapter (4.3), the construction of the first version of ActiveYou II will be described.

## 4.1 Article I: Exploring two subdimensions of participation, involvement and engagement: A scoping review

Published in: *Scandinavian Journal of Occupational Therapy* (2021)

Searching different databases, 5.418 results were found. Of these, 74 abstracts met inclusion criteria. Among these 74 full texts, two were excluded as duplications and 46 did not meet all inclusion criteria. The remaining 26 publications met all criteria and were included in the study. In addition, 11 more publications were added through snowball research.

### 4.1.1 Involvement

Of the 35 included publications, ten discussed the construct of involvement. These originated in marketing/consumer research (Laurent & Kapferer, 1985; Zaichkowsky, 1985) and leisure research (Funk & James, 2001; Funk, Ridinger, & Moorman, 2004; Havitz & Dimanche, 1997; Havitz, Kaczynski, & Mannell, 2013; Jun et al., 2012; Kyle, Absher, Norman, Hammitt, & Jodice, 2007; Suhartanto, Dean, Sumarjan, Kartika, & Setiawati, 2019; Wiley, Shaw, & Havitz, 2000). Within healthcare and rehabilitation, no publications were found that specifically discussed the construct of involvement. It is important to note that multiple authors within leisure research referred to prior research done by consumer research (Havitz & Dimanche, 1997; Kyle et al., 2007; Wiley et al., 2000).

All publications defined involvement as a multidimensional construct. In consumer research, involvement is defined as a *'person's perceived relevance of the object based on inherent needs, values, and interests'* (Zaichkowsky, 1985, p. 342). Building on that, leisure research defines involvement in leisure activities as *'an unobservable state of motivation, arousal or interest toward a recreational activity or associated product'* (Havitz & Dimanche, 1997, p. 246). Note, however, that the labels for the four dimensions changed from *'importance', 'pleasure', 'sign'* and *'centrality to lifestyle'* used by Havitz and Dimanche (1997) to '*attraction', 'centrality', 'social bonding', identity affirmation'* and *'identity expression'* (Havitz et al., 2013; Jun et al., 2012; Kyle et al., 2007). The latest publication included in the review (Suhartanto et al., 2019)

argue for the dimensions of *'importance', 'centrality'* and *'self*-expression' to be the most important. All authors agreed that involvement is an intrinsic and unobservable construct. However, it is expected to influence the individual's behaviour.

With regards to participation, the level of involvement in its different dimensions might affect whether the individual will attempt to participate in the activity. In contrast, the quality of the participation experience – both positive and negative – will influence the individual's level of involvement and in turn influence his/her motivation for future participation.

### 4.1.2 Engagement

Research on the databases found 27 publications for the construct of engagement. Of these, seven originated in the field of management or economics (Bhuvanaiah & Raya, 2014; Harashitha, 2015; Kahn, 1990; Kim, Park, & Kwon, 2017; Kumar & Pansari, 2016; Madan, 2017; Megha, 2016); 10 from educational psychology (James J. Appleton, Christenson, & Furlong, 2008; James J. Appleton, Christenson, Kim, & Reschly, 2006; Axelson & Flick, 2010; Dhanesh, 2017; Finn & Zimmer, 2012; Fredricks, Blumenfeld, & Paris, 2004; Fredricks, Bohnert, & Burdette, 2014; Hollingshead, Carnhan, Lowrey, & Snyder, 2017; Liem & Martin, 2012; Moreira et al., 2015); and nine from healthcare and rehabilitation (Alegria et al., 2014; Bright, Kayes, Worall, & McPherson, 2015; Graffigna, Barello, & Bonanomi, 2017; G. King et al., 2017; G. King et al., 2014; Kortte, Falk, Castillo, Johnson-Greene, & Wegener, 2007; Lequerica & Kortte, 2010; Mayhew et al., 2019; Rieckmann et al., 2015). As with involvement, most authors saw engagement as a multidimensional construct, apart from Algeria and colleagues (2014), who saw engagement mainly as attendance. Furthermore, most authors saw engagement bound to a specific setting and role the individual was to fulfil in that setting. These could be the role of an employee at work (Bhuvanaiah & Raya, 2014; Harashitha, 2015; Kumar & Pansari, 2016; Madan, 2017; Megha, 2016), a student at school (James J. Appleton et al., 2008; James J. Appleton et al., 2006; Axelson & Flick, 2010; Finn & Zimmer, 2012; Fredricks et al., 2004; Fredricks et al., 2014; Hollingshead et al., 2017; Moreira et al., 2015) or a patient/client in a rehabilitation setting (Graffigna et al., 2017; G. King et al., 2017; G. King et al., 2014; Kortte et al., 2007; Mayhew et al., 2019; Rieckmann et al., 2015).

In all three fields, researchers referred to three main dimensions of engagement: an observable dimension of behavioural engagement (e.g. attendance, frequency, duration, time on task) and two unobservable dimensions of cognitive engagement (e.g. self-regulation, relevance for future endeavours, personal goals, autonomy) and affective/emotional engagement (e.g. feeling of identification, sense of belonging, relationships with other participants/teachers/therapists).

This set-up of the engagement construct resulted in measures that tried to assess the unobservable dimensions of engagement as mainly self-administered instruments (James J. Appleton et al., 2006; Graffigna et al., 2017; Liem & Martin, 2012). Only the field of healthcare and rehabilitation relied on questionnaires or protocols administered by the therapist (G. King et al., 2017; Kortte et al., 2007; Mayhew et al., 2019).

### 4.1.3 Discussion: Influence of the scoping review on the use of the participation construct and the measure development

The aim of the scoping review was to answer the following research question:

> Are there definitions for the constructs of 'involvement' and 'engagement' suitable for measurement development in other fields of research, which can be transferred to healthcare and rehabilitation?

The scoping review revealed definitions for both constructs. While there is no clear distinction for the two constructs within healthcare and rehabilitation thus far, based on the literature from different fields of research, *involvement* and *engagement* can be differentiated.

*Involvement* is seen as a more general motivation or interest towards an activity and is unobservable. For further research in this thesis, the definition of leisure involvement was adapted (Havitz & Dimanche, 1997), not least because the aim of this project was to develop a measure for participation in leisure activities. Furthermore, the definition worked as a basis for the development of a measure of involvement (in leisure research) that has proven its psychometric properties (Kyle et al., 2007).

*Engagement*, in contrast, is always connected to a specific setting and role that the individual fulfils. Different settings for participation may lead to a different role and specific differences in cognitive and affective engagement. For example, an individual may participate in football: during physical education lessons at school as a student, with the formal goal of getting good grades; unorganised with his friends during his free time to socialise and have fun; and in a football club to improve their skills and compete. Therefore, measures are always context-specific. Summarising fields of research, engagement was defined as the 'individual's behavioural, cognitive and affective investment during role performance'. Connected to participation, the combination of the three engagement dimensions describes the individual's participation experience.

However, it cannot be denied that the two constructs – involvement and engagement – influence each other. Such influence can be seen in Figure 5. Good participation experiences will, in the long term, influence the individual's level of involvement. The general level of involvement will influence the individual's willingness/motivation to participate in the activity. This loop effect may – depending on whether participation experiences are positive or negative – facilitate participation or lead to drop-out or refusal of participation.

In comparison to previous definitions for involvement in the ICF (World Health Organisation, 2001) or both involvement and engagement in the fPRC model (Imms et al., 2017), the definitions found in this scoping review, particularly with more detailed sub-dimensions, give a sharper definition of these constructs. The ICF defined involvement rather loosely in a single footnote and gave no specifics for engagement. The fPRC model defined both constructs. However, these definitions were rather broad and not in line with the findings of the scoping review. The definition for involvement by Imms and colleagues (2017) is understood as engagement in most literature included in the scoping reviews, and most authors refer to engagement in the fPRC model as involvement.

Having a more detailed definition, in theory, should help develop a more valid measure (Adair et al., 2018; Himmelfarb, 1975). It is important to consider that ActiveYou II is meant to measure multiple activities in multiple settings. As engagement is context-specific, an instrument like ActiveYou II cannot aim to measure validly the level of engagement of children and youth with disabilities. For example, a child might participate in a certain activity—say, football—in multiple settings. In one setting, the child might be kicking on the pitch with his peers in an unorganised manner. In this setting, the main motivation would be fun, social interaction, and building positive peer relationships. Another time, the same child might be training at a football club. Although fun might also be a motivation here, there is the intention to train to improve activity-specific skills and give the best possible performance in upcoming competitions/tournaments. Therefore, the child takes part in the same activity; however, the motivation for doing so (social interaction vs. training for performance) and the relevance to future life (having positive peer relationships vs. succeeding in competitions) differ. As a result, the level of engagement in both settings differs and needs to be assessed individually for every setting. ActiveYouII can, at best, evaluate the general level of interest or attraction towards the different activities, since it does not evaluate all the different settings the child participates in each and every activity. One can conclude that it would be most feasible to measure the level of involvement or, more specifically, the dimension of attraction within the new instrument.

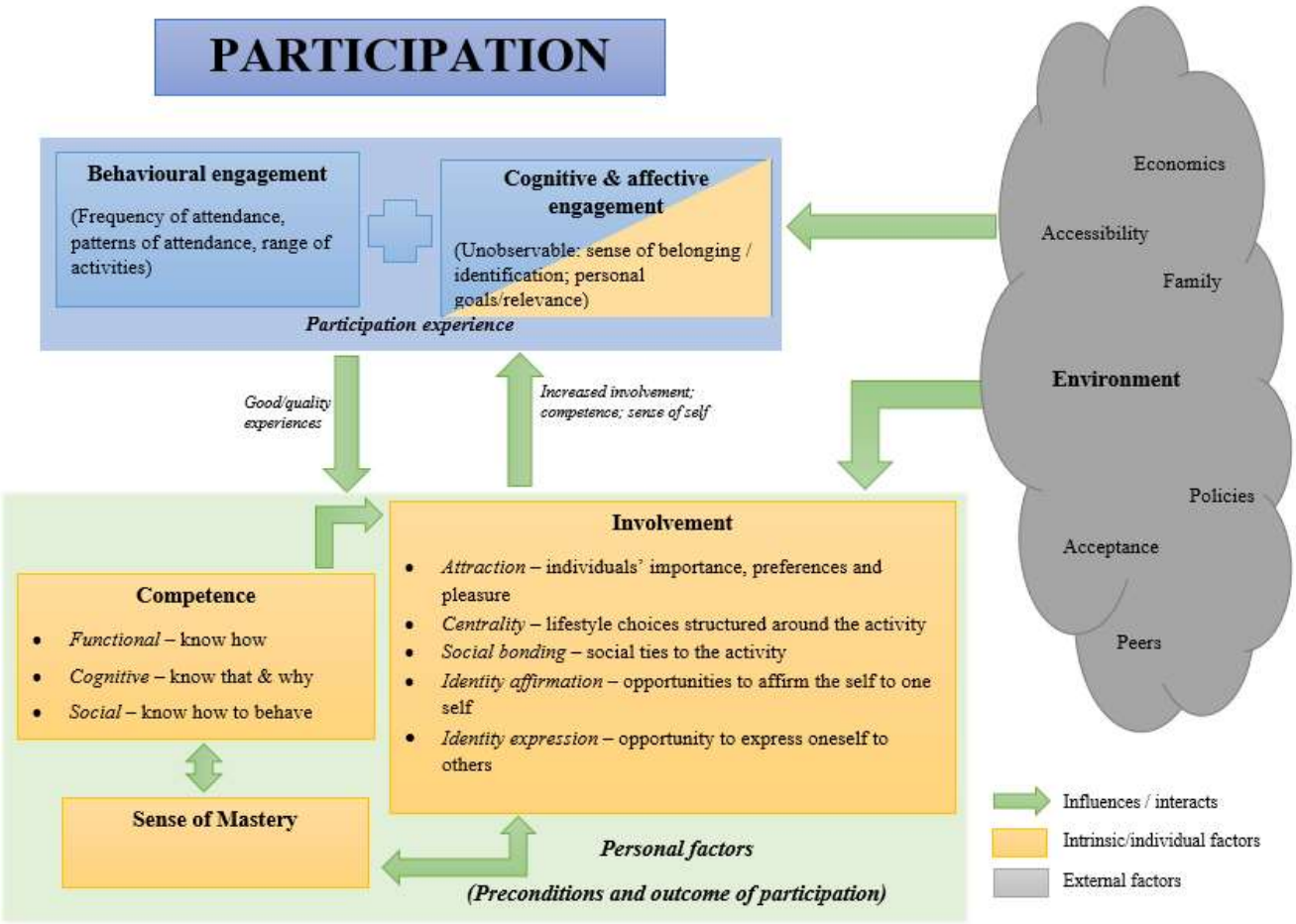


Figure 5: Understanding of 'participation' after the scoping review

## 4.2 Article II: Perceived facilitators and barriers for participation in leisure activities in children with disabilities: perspectives of children, parents and professionals

Published in: *Scandinavian Journal of Occupational Therapy* (2019)

There were 61 interview participants. Of the 61 participants, 32 parents participated in seven interviews, 20 professionals in five interviews and nine children in four interviews. As the analysis of the interviews was based on the model of factors facilitating and hindering participation by G. King et al. (G. King et al., 2003), the results were also structured according to this model (definitions in table 4).

### 4.2.1 Child factors

The first overarching dimension was 'Child factors'. Here, the children who participated in the interviews talked mostly about their different activity preferences. They reported only on barriers – with regards to physical, cognitive or communicative function – when talking about other children. One boy, for example, questioned how another girl in the group interview could participate in dancing since she was sitting in a wheelchair. This may be a result of the young

age of the participating children (mean age 11.1 years). Parents and professionals, on the other hand, talked much about how children become demotivated and might drop out of activities when the ability gap, in contrast with their non-disabled peers, becomes more apparent with age, especially during their early teenage years. Both parents and professionals mostly saw the following barriers within the 'Child factors' dimension:

- Increasing ability gap compared with non-disabled peers → demotivation, low self-esteem, drop-out
- Overall level of energy, fatigue
- Attention deficits compared with non-disabled peers
- Unpredictable situations that could lead to resistance to further participation
- Parents or assistants might not be able to assist children in their preferred activities

In contrast, parents and professionals mentioned only a few facilitating factors and strategies in this dimension:

- Finding activities or a niche within an activity that suited the children's abilities
- Masquerading: finding an activity where the disability was not visible
- Adapting the activity to the child's needs/abilities
- Focusing on individual activities and one-on-one support to cope with attentional issues
- Considering the child's preferences in the choice of activities.

### 4.2.2 Family factors

The dimension of 'family factors' was mainly covered by the participating parents and professionals. The main barriers here were:

- Activities available only at long distances
- The child's need for support during participation
- Expenses for one-on-one support or lessons
- Conflicts with the working hours of the parents and organised activities
- Coordination of leisure activities, especially with multiple children in one family
- Parental exhaustion from work and everyday life
- Social isolation
- Parents' mental stress due to coping with the child's disability or from trying to protect children from negative experiences
- Parental physical/mental restrictions due to own disability/illness

Parents and professionals alike found several facilitating factors. Both groups agreed that support from parents were the most relevant facilitating factor for participation in leisure activities. Other facilitators and facilitating strategies included:

- Using gaming to facilitate social participation (e.g. through online multiplayer games) or physical training (e.g. using Wii Sports, EA Sports Active, Xbox Your Shape or Happy Rehab$^{TM}$)
- Working part-time (with economical support from the Norwegian welfare system)
- Supporting the child's autonomy during participation
- Using parents and siblings as active role models

### 4.2.3 Environmental factors

For the third category, 'environmental factors', children talked the most about positive peer relationships. Some mentioned that they changed activities or sports clubs based on negative peer interaction, but overall a more positive attitude dominated the contributions of the children participating in the interviews. Parents and professionals had a more differentiated view, with many factors being both barriers and facilitators, depending on the situation. In the view of parents and professionals, the main barriers were:

- Lack of physical accessibility
- Little variety of (adapted) activities, especially in rural areas
- Restrictions in (local) legislations and regulations, especially on personal assistance
- Lack of knowledge/competence of activity leaders about children with disabilities (also based on the structure of Norwegian sports clubs, where parents often worked as voluntary activity leaders during their free time)
- Other persons (e.g. friends, parents of peers) perceiving insurmountable barriers that actually were easy to handle
- General lack of thoughtfulness in society
- Activity leaders with an exclusionary attitude
- Peers with an exclusionary attitude
- Lack of information
- Lack of informal support
- Unmotivated/stressed local professionals/unclear responsibilities

In contrast, the main facilitators identified were:

- Adapted/accessible public areas

- Living in urban areas with a larger variety of available activities
- General legislation and support from the Norwegian welfare system
- Leisure/personal assistants
- Active and knowledgeable activity leaders with an inclusive attitude
- Peers with an inclusive attitude
- Inclusive peer groups consisting of children both with and without disabilities
- Informal support from relatives and friends
- Exchange with other parents of children with disabilities
- Motivated and knowledgeable professionals
- Advocacy groups
- Local welfare offices

### 4.2.4 Discussion: Influence of the interviews on the participation construct and measure development

The purpose of the second article was to find facilitators and barriers to participation in leisure activities (specific to the Norwegian setting) to include in the new instrument—ActiveYou II. Following from this, the research question for the second article was:

> What kind of facilitators for and barriers to participation in leisure activities do children and youth with disabilities and their families experience in Norway?

The interview process was able to show several specifics of the Norwegian setting. The interviews with children, parents and healthcare professionals showed how incorporating different perspectives improved the research process. It was of special significance to incorporate the perspectives of children. They mostly focused on – or even perceived – facilitators for participation in leisure activities, and not so much on barriers. As ActiveYou II is supposed to be a self-reported instrument, this result supported the reasoning about including facilitating factors for participation into the instrument. In addition, this also brings forward the fact that most children would possibly need assistance when reporting barriers—especially financial barriers or organizational issues that only parents were aware of. This supports the decision of ActiveYou II being a self-reported instrument, with the child/youth as the main respondent, yet, with the possibility of assistance of an adult guardian when administering the instrument.

Furthermore, the interviews showed differences from international studies. Financial aspects were less relevant than in studies from, for example, Rimmer and colleagues (2004) in the

United States of America, Shields and Synnot (2016) in Australia, or Wright et al. (2019) in Australia. Most financial barriers, like less income or extra costs for special equipment or assistance, were often compensated by the Norwegian welfare state, according to the parents and professionals. One main barrier, especially in rural areas, was the availability of appropriate activities within a reasonable distance. Parents also reported, as a barrier, a lack of information on where to find activities or where to receive support. Summarising the interviews, a list of facilitators and barriers for a first version of ActiveYou II was developed. After discussions with experienced researchers (Ph.D. supervisors) and the leader-group of BHC, these were supplemented with some factors that were not that relevant in the Norwegian setting, but important to know in order to be able to compare results with international studies. This list consisted of the following factors:

Facilitators:

- Somebody tells me where I can participate
- Activity is available close by
- Participation is free
- Participate together with family
- Participate together with friends
- Mom, dad or siblings assist me
- I have a personal assistant or leisure assistant
- The activity leader adapts the activity
- I experience no pain or fatigue
- I have the equipment I need

Barriers

- I don’t know if there are possibilities to participate
- Activity is not available where I live
- Too far away
- The date does not work for me
- Too expensive
- Nobody can assist me
- The others aren’t nice to me
- The activity leader doesn’t take care of me
- I’m too exhausted

Because ActiveYou II is a generic instrument with the possibility of changing out activities in different settings, it was important to focus on both physical and leisure activities during the interviews, even though all the activities included for the first application of ActiveYou II at BHC were physical activities (see Appendix B4).

Regarding the understanding of participation, the interview process – especially the analysis – showed that the framework factors affecting the recreational and leisure participation of children with disabilities, developed by King and colleagues (2003), were efficient for explaining the perspectives of children, parents and professionals. Therefore, the pragmatic framework of participation used to develop ActiveYou II, and to understand participation, was supplemented with this framework. Figure 6 illustrates the pragmatic working model for participation. Table 4 gives an overview of the definitions and background of the included parts of the constructs of the pragmatic model for participation.

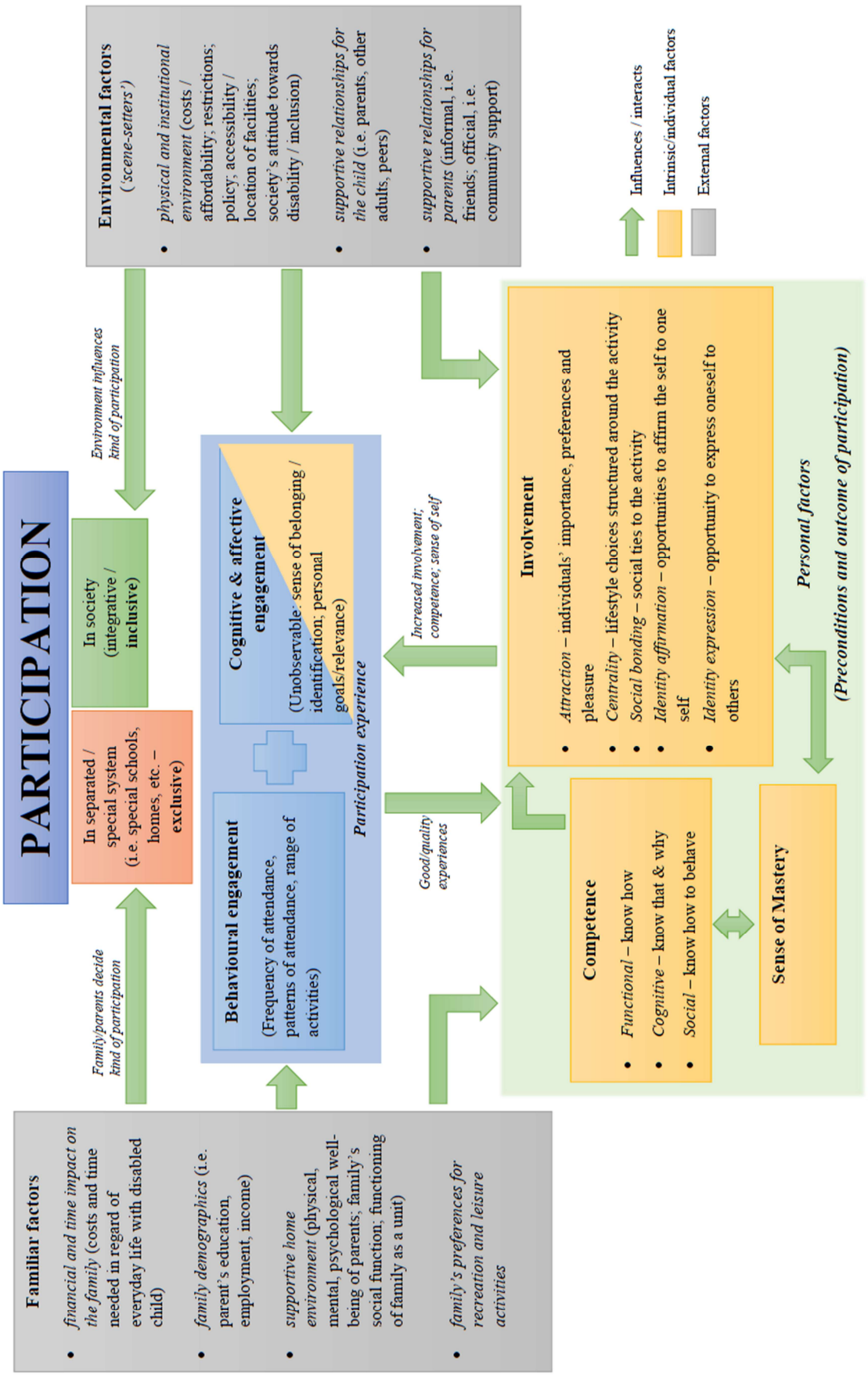


Figure 6: Pragmatic working model of participation for ActiveYou II

Table 4: Definitions included in the pragmatic working model of participation

| Part of the construct | Definition/description |
|---|---|
| **Participation** | Participation is a multidimensional construct describing both observable and unobservable components that contribute to a person's partaking in life situations |
| **Participation experience/engagement** | The individual's behavioural, cognitive and affective investment during role performance |
| **Behavioural engagement** (James J. Appleton et al., 2006) | Refers to a range of actions that reflect involvement in activities (attendance, frequency, time-on-task) |
| **Cognitive engagement** (James J. Appleton et al., 2006) | Refers to self-regulation, relevance for future endeavours, personal goals and autonomy |
| **Affective engagement** (James J. Appleton et al., 2006) | Refers to feelings of identification and/or belonging and relationship with adults and peers |
| **Involvement** (Havitz et al., 2013) | Involvement is an unobservable state of motivation, arousal or interest toward a recreational activity or associated product – evoked by a particular stimulus |
| **Attraction** | A combination of the individual's importance, preferences and pleasure |
| **Centrality (to lifestyle)** | The extent to which an individual's lifestyle choices and personal investment are structured around an activity |
| **Social bonding** | Explains the social ties that bind the individual to a specific activity |
| **Identity affirmation** | The degree to which a leisure activity offers opportunities to affirm the self to oneself |
| **Identity expression** | How one can express one's self to others |
| **Competence** (Winterton, Delmare Le Deist, & Stringfellow, 2005) | Competence describes a person's innate abilities, emotions, attitudes, skills and knowledge, and the motivation and ability to apply in certain context. |
| **Functional** | Refers to the ability and willingness to execute skills |
| **Cognitive** | Refers to the underlying knowledge and understanding of a task |
| **Social** | Refers to the ability and willingness regarding behaviour and attitudes |

| | |
|---|---|
| **Sense of Mastery** (Pearlin & Schooler, 1978) | Describes the extent to which one regards one's life chances as being within one's own control. |
| **Self-Esteem** (Rosenberg, 1965) | Describes a person's positive or negative attitudes towards oneself |
| **Environmental factors** (G. King et al., 2003) | Refer to physical and social factors that appear to provide important opportunities for people to participate. |
| **Physical and institutional environment** | Absence of cost restrictions; policy barriers and physical barriers; accessibility; and location of facilitations/activities |
| **Relationships for the child** | Support from parents, other adults and peers |
| **Relationships for the parents** | Informal and formal support for parents |
| **Family factors** (G. King et al., 2003) | Refer to circumstances that appear to provide important opportunities for people to participate |
| **Financial and time impact on the family** | Financial and time impact of caretaking of the disabled child on a daily basis |
| **Family demographics** | Parent's education, employment, family income |
| **home environment** | Physical, mental, social well-being of the parents, family's social function, function of family as a unit |
| **Family's preferences for recreation and leisure activities** | Family's preferences for recreation and leisure activities |

## 4.3 Construction of the pilot version of ActiveYou II

Based on the results of articles I and II, a pilot version of the questionnaire was developed. For ActiveYou II to work in conjunction with ActiveYou I, the general design and layout of ActiveYou I, which was developed through a multi-stage process (Dalen et al., 2020), was adapted (see appendix B5). Important aspects of this layout are small slide shows that illustrate each activity and the implementation of three red, yellow, and green smileys as an alternative for a traditional three-point Lickert-Scale. This layout was supplemented with items from ActiveYou II. As the development of ActiveYou I and ActiveYou II have their roots in research done with PAC and CAPE (Hoberg & Nyquist, 2011; Nordtorp et al., 2013), highlights from these studies were implemented in the item selection. Items measuring involvement were adapted from the attraction dimension of the Modified Involvement Scale (MIS) (Kyle et al., 2007), and the item on sense of mastery and self-efficacy was adapted from the Canadian Occupational Performance Measure (COPM). In the case of the MIS, the items were translated

to Norwegian. All formulation of the items was discussed with several experienced researchers (Ph.D. supervisors) and the leader group at BHC.

The activities included in the questionnaire were pre-set because they had to work in conjunction with ActiveYou I. Dalen and colleagues (2020) described the multi-stage process, which led to the 17 activities included in the questionnaire. The intention was to include various activities that represent the most common and popular activities in an actual setting. Therefore, data from a study by Nyquist (2012), using PAC and COPM resulted in the first set of activities, which was discussed with professionals and leaders at BHC and brought forward to a set of 19 activities. After a first pilot test of ActiveYou I, the activities were reduced to 17 and included in both ActiveYou I and the first pilot version of ActiveYou II (Dalen et al., 2020).

The facilitators and barriers were included based on the results of article II and further discussions with the leader groups of BHC.

## 4.4 Article III: Testing ActiveYou II: applying cognitive interviews in improving item quality and applicability of a web-based, self-report instrument on participation in children with disabilities

Published in: *International Journal of Environmental Research and Public Health*

After the theoretical work and group interviews regarding specifics of the Norwegian setting, described in the previous two articles, a first version of the instrument was developed. The main questions of the third article were:

(1) Can cognitive interviews with children and youth (target group) improve item quality and applicability of ActiveYou II?
(2) Which adjustments are needed before advancing in the development process of ActiveYou II?

### 4.4.1 Cognitive interviews

Nine children (two boys and seven girls; mean age 12.6 years) participated in cognitive interviews. Each item was shown to the participants via a projector. At the same time, the participants could read and answer the questions on a printed version of the questionnaire (see Appendix B4). In addition to the children, five mothers participated to observe the interview situation or assist their children.

The interviews showed that most of the children found the questionnaire difficult to answer. The main issues lay in the comprehension- and response-phase of the question-answer-model

(Tourangeau, 1984). Three of the five children who had their mothers seated in the background turned to them (verbally or non-verbally) asking for their help in addition to the assistance from the interviewers. Two of the mothers assisted verbally from the background, while one mother seated herself close beside her child to assist. All the children could read the questions. However, some did not have enough reading comprehension skills to fully comprehend the intent of the questions. The main concern for the children was specific terminology. Words like '*activity leader'*, '*adapt'* and '*relative'* were difficult for the children to understand. Most of them had no idea what these words meant or could not explain them. In order to enhance comprehension, these words needed to be changed. After explaining the terms, alternative formulations were found.

Regarding the general design of the questionnaire, the children experienced the illustration of the activities with pictures positively. They also perceived the use of smileys for the three-point Likert scales as easy to use. However, they had several other issues.

From their everyday life, the participating children were mostly familiar with weekly schedules. When asked about participation frequency, they tended to answer in categories like *'I do this every Friday'* or *'I do this every day'* and had problems converting these to the given response-alternatives like '*1–2 times a week'* or *'3–7 times a week'*. Eventually, due to issues programming the online survey, a weekly schedule for answering the participation frequency was not possible.

In addition, items with several written response alternatives like 'setting', 'facilitators' and 'barriers' were perceived as overwhelming for the children. Besides issues with terminology, many children used a lot of time reading all the alternatives and understanding them. Participants – especially the participating mothers – argued to combine different alternatives. However, for the setting of participation, participants requested an additional category '*together with schoolmates*', since many children tended to participate in leisure activities in the school setting outside class (e.g. during free minutes or after school using school facilities), yet this kind of participation was not represented in the response alternatives.

Another set of items that caused confusion among the participating children were items on the individual's 'level of involvement' ('*It is fun to do this activity'* and *'The activity is important to me'*) and 'sense of mastery' (*'How well do you think you can do the activity'*). Many children did not comprehend the difference between the items, especially whether the activity was important to them and whether the activity was fun to do. Even when mothers tried to explain

the difference to their children, they did not follow their reasoning. Children argued that they did activities because they were fun to do and that was also why they were important to them. Therefore, one of the two items was removed after the cognitive interviews (‘*The activity is important to me’*).

Regarding facilitators and barriers – as known from the group interviews (see article II) – children mostly focused on factors facilitating their participation. They could not relate to most of the barriers, especially economic barriers. These oftentimes were mentioned by the mothers who were participating in the cognitive interviews.

Following the cognitive interviews, the questionnaire was adjusted according to the results.

### 4.4.2 Discussion: Influence of cognitive interviews on measure development

The results from the cognitive interviews showed the potential of this method in order to improve item quality and applicability. Combining the method with the question-answer-model by Tourangeau (1984) proved to be especially resourceful. Here the phases of comprehension and response were especially relevant. Cognitive interviews showed more specific issues with terminology, formulations and overall comprehension. This first-hand information from the target population can be applied to adjust the instrument before further psychometric testing. Several items were adjusted in their formulation, and the vocabulary was changed according to the suggestions of participants in the interviews. In addition, the item ‘*The activity is important to me’* was deleted because it only confused children due to its similarity to the item *‘It is fun to do this activity’*. This decision was made based on the reasoning that other instruments – including the subjective perspective of participation – also focused mainly on attraction/enjoyment rather than on importance (B. Adair et al., 2018). By including one item focusing on attraction towards an activity, the possibility remained to compare the results of ActiveYou II with other instruments. A detailed overview of the changes made to the instrument after the cognitive interviews is available in the published version of the article.

## 4.5 Overarching results on the children’s perspective on participation

Children were included as respondents in group and cognitive interviews. Data from this thesis showed that the parents’ perception of the child’s participation was not automatically identical to the child’s perspective. A prominent example is a case where both the mother and her son participated in group interviews. When asking what kind of at-home activities the child participated in, the mother explained:

*"We are living at a farm so there is a lot to do all the time. My son loves to help out, feeding the animals, helping his father with all the machinery and all this stuff…"*

However, when asking the children whether there were any activities they had to do, but did not really like doing, the son stated:

*Boy: 'I'm allergic to work.'*

*Researcher: 'What do you mean by that?'*

*Boy: 'We are living at a farm, and I have to help out all the time: feeding the calves and assisting my dad with fixing all the machinery. I just hate it.'*

This example shows how the mother's perception just did not mirror the child's perspective – and was completely opposite. This supports the argument of King (2013) that the parental and individual perspective can differ. Additionally, as discussed in the second article, on facilitating and hindering factors, children tended to have a more positive mindset towards their participation. Whereas parents and professionals named many hindering aspects, the children almost exclusively focused on facilitating factors, like enjoyment and positive peer relationships.

# 5

## 5. Reflection on the project and future direction

The original aim of this project was purely measure development. However, during the research, process multiple aspects arose that warrant further discussion. First, the development and future steps of ActiveYou II need reflection to finalize the instrument for clinical use. Second, children were the main respondents of the study, both in group and cognitive interviews and moving on for testing the new self-reported instrument. Not everything went as planned while developing the instrument and addressing children with disabilities. Several considerations need to be addressed. Third, to develop ActiveYou II, the project required clear definitions of the main constructs of participation. Therefore, a working theory was developed. The results from the working theory in this thesis are discussed in light of the discussion on the conceptualisation of participation in the ICF.

### 5.1 The state of ActiveYou II

The main goal of this thesis was to develop a web-based instrument to measure participation in (physical) leisure activities for children and youth with disabilities. The current state of ActiveYou II will be discussed in relation to the Consensus-based Standards for the selection of Health Measurement Instruments (COSMIN) guidelines (Mokkink, Prinsen, Bouter, de Vet, & Terwee, 2016; Prinsen et al., 2016). These guidelines aimed to *'improve the selection of outcome measurement instruments both in research and in clinical practice by developing tools for selecting the most appropriate instrument'* (Mokkink et al., 2016, p. 105). As ActiveYou II is an instrument aimed towards clinical use and supposed to measure outcomes of rehabilitation interventions, it seems logical to use these guidelines as an orientation.

In selecting an instrument, researchers and clinicians should follow the four steps outlined by (Prinsen et al., 2016):

- Step 1) conceptual considerations
- Step 2) finding existing outcome measurement instruments
- Step 3) quality assessment of outcome measurement instruments
- Step 4) generic recommendations on the selection of outcome measurement instruments for outcomes

Regarding 'Step 2', the development of ActiveYou II was started because of a lack of self-reported instruments measuring patterns of participation in leisure activities, including facilitating and hindering factors for children and youth with disabilities, culturally validated for the Norwegian setting. 'Step 4' can only be decided by the individual researchers and

clinicians who might want to apply ActiveYou II. Therefore, this discussion focuses on 'Step 1' and 'Step 3'. This discussion also gives direction for future research.

### 5.1.1 Conceptual considerations of ActiveYou II

According to the COSMIN guidelines, the first step in selecting an instrument is agreeing on the construct to be measured and the target population (Prinsen et al., 2016). Therefore, it is important for a measurement to answer these questions. In the case of ActiveYou II, the target population is defined as children and youth with disabilities aged 5–17 years old. The COSMIN guidelines suggest to further consider specific subgroups (e.g. by age, gender or disability characteristics). Thus far, such considerations are hard to be make for ActiveYou II. The target age group for the new instrument was pre-set based on the setting the instrument was developed for, as described in 2.6. There is too little information on which subgroups the instrument is most suitable for thus far. As ActiveYou II is meant to be generic, and the photos can be changed according to different target groups, this needs to be further explored in the actual target group, using cognitive interviews.

However, the conceptual considerations of ActiveYou II are clearer. Following the working theory, all items have a clear definition on which subconstructs and aspects of participation are measured with the instrument. These aspects are:

- Frequency of participation
- Diversity of activities
- Setting for participation
- Sense of mastery
- Involvement in the activity (especially, the attraction towards the activity)
- Facilitating factors
- Hindering factors

Therefore, ActiveYou II is attractive for researchers, clinicians and service providers who want to measure these aspects. Possible applications for the instrument could be:

- Researching differences in these aspects between different subgroups in a cross-sectional study
- Evaluating effects of an intervention that aims to affect one or several of these aspects using a pre-test/post-test design.
- Studying trajectories of participation over time

### 5.1.2 Quality assessment of ActiveYou II – Future steps in development

According to the COSMIN guidelines, nine properties can be sorted into the three categories of reliability, validity and responsiveness (Mokkink et al., 2016; Prinsen et al., 2016). As ActiveYou II thus far has been tested only for a few of these aspects, the discussion will focus primarily on if and how these properties should be tested in future studies.

Since ActiveYou II is supposed to be a web-based instrument, future development will include online-research, which leads to several issues that need to be taken care of. Many researchers have argued about the advantages and disadvantages on online research (Dzeyk, 2001; Fängström et al., 2016; Kraut et al., 2004; Zerback, Schoen, Jackob, & Schlereth, 2009). This is especially relevant now because, with easily available internet, the use of online surveys has become increasingly popular (Kraut et al., 2004; Zerback et al., 2009). Dzeyk (2001) explains several advantages and disadvantages of online research:

- Advantages
    - No geographical bindings
    - Easy recruitment (via email)
    - Respondents choose where and when they want to answer
    - Very economical
        - Less time for recruitment
        - Less time and money spent on travelling during recruitment and data collection
        - Cost savings due to not printing questionnaires, or postage
        - Time saving because data often does not have to be entered manually into SPSS or Excel
- Disadvantages
    - Harder to collect a representative sample
    - Some topics cannot be researched online easily
    - Possibility of ending up with an *ad hoc* study
    - Higher risk of data abuse
    - Issues concerning collecting consent online
    - Less chance of control (e.g., who answers the questionnaire; where, when and how seriously the respondent takes the process)

For future steps in the development of ActiveYou II, it is important to address and minimize the disadvantages of online research. This is important for later studies regarding the

psychometric properties of ActiveYou II. The main focus should lie on carefully informing participants about the study. In addition, contact information to the researchers should be included in all information given to the participants to assure they could contact them easily. Furthermore, to avoid data abuse, the questionnaire should only be available with an account and password randomly created for each participant. To avoid an ad hoc sample, data collection should be planned carefully and coordinated with the gatekeepers to capture samples with as much variety and coverage on the target group as possible. In many aspects, future studies can also rely on experiences from the validation-process of ActiveYou I (Dalen, 2019).

For reliability, it is important to test the instrument for internal consistency, reliability and measurement error (Mokkink et al., 2016). Both reliability and measurement error can be tested by applying a test-retest study design. According to De Souza and colleagues (2017), a meaningful test-retest design should consist of a sample of at least 50 participants.

As the instrument is a web-based instrument, it will be challenging to assure that participants fulfil the optimal criteria of similar test conditions (e.g. setting, assistance), which are important to asses test-retest reliability appropriately (Moosbrugger & Kelava, 2012). This could be addressed by using institutions that could assure these conditions, such as testing children in their school environment (with teachers as a stable assistant, if needed), as done in the cultural validation of PAC and CAPE (Nordtorp et al., 2013). Alternatively, children could be tested during weekly appointments with their physiotherapist or other professional or testing children that participate in a stationary intervention. The latter would presuppose that the intervention does not affect the measured construct.

De Souza and colleagues (2017) argue that the optimal time interval of the two tests is between 10 and 14 days. In contrast, Moosbrugger and Kelava (2012) argue there is no concrete time interval. They maintain that the time interval depends on different aspects, such as a possible memory effect of the respondents or whether one can expect systematic or unsystematic change in the responses. Longer test intervals will make the design less susceptible to memory effects but more susceptible to unsystematic changes, and vice versa.

Testing the instrument for internal consistency may be more difficult. Usually a test for internal consistency is done by applying Cronbach α, split-half reliability or Kuder-Richardson-20 (KR-20) calculations. With ActiveYou II, several issues make the application of these calculations rather challenging. First, Cronbach α, or KR-20 is designed to test internal consistency for unidimensional constructs (De Souza et al., 2017; Streiner, 2003). However, participation is a

multidimensional construct, and ActiveYou II aims to measure several aspects of this construct, which make the use of Cronbach α inappropriate (Moosbrugger & Kelava, 2012). One possibility is to test the different dimensions within the construct for internal consistency individually. As most of the aspects within the instrument consist of dichotomous items (e.g. a facilitator or barrier either exists or does not exist), KR-20 calculations should be prioritised before Cronbach α because the latter does not work for these kinds of items (De Souza et al., 2017). Even with KR-20, there are some logical considerations because one cannot really expect that, for example, one barrier (e.g. I'm too exhausted) would predict another barrier (e.g. The activity is too expensive). Moosbrugger and Kelava (2012) argue that even though tests for internal consistency are widespread and highly valued, they may not be relevant or meaningful for all instruments. In the case of ActiveYou II – based on the aspects discussed here – such tests do not seem meaningful.

For validity, the COSMIN guidelines evaluate instruments based on content validity, construct validity and criterion validity (Mokkink et al., 2016). Moosbrugger and Kelava (2012) argue that there is no general recipe on what kind of validity needs to be tested for each individual instrument. This decision depends on what the instrument measures and what the field of application the instrument is aimed for. Content validity measures the degree to which the instrument reflects the measured construct (Field, 2019). Usually, this aspect is tested using a qualitative approach, with an expert committee rating the instrument, followed by a quantitative approach using the content validity index (CVI) (De Souza et al., 2017).

Returning to the target group, more cognitive interviews – as done by Liljenquist and colleagues (2019) – will help to assure content validity. According to Prinsen and colleagues (2016), an instrument can fulfil requirements for content validity by reporting all aspects of the construct that are supposed to be measured: the relevant target population, the context in which the instrument should be applied and the fundamental definitions of the constructs measured linked to the items. Due to the extensive theory work in the beginning of the project, these criteria can be met for ActiveYou II. However, additional cognitive interviews – using an adjusted version of ActiveYou II based on the cognitive interviews presented in article 3 – with the target population are assumed to be an adequate method for testing the instrument for content validity (Moosbrugger & Kelava, 2012). Additionally, a traditional approach using an expert committee consisting of experienced researchers and clinicians could be applied in a future study.

For construct validity, that consists of the three sub-dimensions of structural validity, cross-cultural validity and hypotheses testing (De Souza et al., 2017; Mokkink et al., 2016), the

COSMIN guidelines focus on testing the instrument for structure validity. This can be tested by applying a Rasch analysis or item response theory (IRT). However, for nominal items – as used in ActiveYou II – a Rasch analysis is not an appropriate approach and is therefore not relevant for further testing of ActiveYou II.

For cross-cultural validity, the COSMIN guidelines call for evidence that there is no difference between multiple language versions of the instrument. As ActiveYou II only exists in Norwegian thus far, there is no way to collect data for cross-cultural validity at this point. At the same time, ActiveYou II is designed specifically for the Norwegian setting, especially regarding facilitating and hindering factors for participation. These factors may vary internationally, as discussed in Article 2, so the question is how useful the instrument would be outside of the Norwegian, or maybe Scandinavian, setting. From experience from the cross-cultural-validity of PAC and CAPE, were results for Norway and Sweden were very similar – as shown by Ullenhag et al. (2012) – other Nordic countries might be the first ActiveYou II could be transferred to. Consequently, testing ActiveYou II for cross-cultural validity is neither relevant nor meaningful in the current state of the instrument.

Criterion validity, measuring whether an instrument measures what it claims to measure (Field, 2019), is usually tested by comparing the instrument against a gold standard (De Souza et al., 2017). ActiveYou II could be tested against the Norwegian version of CAPE, which has been tested for its psychometric properties (Hoberg & Nyquist, 2011; Nordtorp et al., 2013). Using CAPE, the aspects of participation frequency and involvement/attraction could be compared. However, this would not be a traditional test for criterion validity but rather a test of how data from these two measures for participation correlate.

The last property the COSMIN guidelines apply involves evaluation of instruments meant to assess responsiveness. To give any information about this property, larger studies are needed to test results against hypotheses set beforehand.

### 5.1.3 Considerations regarding the broad target group of ActiveYou II

This Ph.D. project was closely connected to the rehabilitation setting at BHC and the intended application within the Local Environment Model. The target group for the new instrument was pre-set to cover children and youth from age five to 17, and was not open for discussion during the research process. Other measures like PAC and CAPE, designed as self-administered measures for a target group ranging from age 6 to 21 years (King et al., 2004), are facing similar

challenges. It is, however, important to reflect on the advantages and disadvantages of such a broad target group, with regard to the age range and wide range of disabilities.

As explained in chapter 3.3, age implies different levels of reading skills, comprehension, and levels of reflection on own experiences, and consequently different abilities to respond to the questionnaire. It is expected that most children over the age of 12 can answer the self-administered standardized questionnaires (Heath et al., 2009). That means the youngest children in the target group would only be capable of answering short surveys in a guided manner. Therefore, it was expected that children younger than 12 years would need assistance. This need for assistance became even more apparent during cognitive interviews. Although the children who participated in the interviews were on the average older than 12 years, they needed assistance to answer the questionnaire. Consequently, ActiveYou II was designed as a self-reported rather than a self-administered instrument. This implies that even though children are the main respondents, it was expected that they might need assistance from an adult guardian. Future studies should investigate how many children require such assistance.

The age range was discussed during the group interviews. Professionals highlighted the challenges in developing an instrument for such a wide age range. It was determined that the design be orientated more towards younger children. For example, using smileys instead of a standard three-point Likert-Scale, illustrating the activities using small slide shows, and keeping the instrument as simple as possible would make the instrument easier for younger children to use. The use of such alternatives is also supported by literature (Read & Fine, 2005), as explained in chapter 3.3. The first cognitive interviews confirmed that the children could work with the general design but had difficulties regarding the comprehension of some items or formulations and transforming their answers to the given response alternatives. After adjustments, further individual cognitive interviews are necessary. These should also include children below the age of 10 years, and should examine how the young ones can answer the questionnaire (with assistance).

A second important aspect to consider was the wide range of disabilities included in the target group. The Local Environment Model at BHC involves children with all kinds of disabilities, so there was a need for an instrument that addresses all these children and youth. This comes with a couple of challenges, advantages, and disadvantages. Research done with Norwegian versions of PAC and CAPE (Hoberg & Nyquist, 2011) showed that children with learning disabilities particularly struggled with the instruments. Therefore, the goal for ActiveYou I and II was to make them more applicable for these groups of children. In group

interviews, parents contributed with suggestions on adjusting an instrument for this group of children. The main points were to illustrate the activities (as done with the small slide shows for each activity); have a few questions per page; keep the language simple, and use the system of a weekly schedule to report participation in the different activities (something most children were familiar with), instead of written categories. The option of a weekly schedule could not be executed due to technical difficulties. Therefore, the same issue came up again during cognitive interviews, where children struggled with these written alternatives for their participation frequency. In conclusion, it seems logical to further investigate the possibilities of including a weekly schedule as a method of reporting participation, to make the instrument more applicable.

In addition, different disabilities pose different challenges with participation in general and for the design of the questionnaire. Therefore, a questionnaire that aims to meet a wide variety cannot be optimized for each sub-group. For example, the implementation of smileys instead of the three-point Likert-scale was based on children's previous experience with smileys when using ActiveYou I (Dalen et al., 2020). During the group interviews in this thesis, most parents explained that their children could work with this design very well. However, some parents expressed that children with visual impairments (e.g., color blindness) or autism spectrum disorder (ASD) or attention deficit disorder (ADD) had some challenges. For example, using the different facial expressions on the smileys and different colors simultaneously were too many stimuli to process for children with ASD or ADD.

On the other hand, using only colors did not work for children with color blindness. Similar issues appeared with the implemented slideshow for the activities. These included different modes for performing each activity (i.e., sitting or standing alpine and cross-country skiing). While it was helpful for most children to visualize the activity, some children with ADD or ASD became distracted or caught up in some details in the pictures, as parents in group interviews reported from their experience with ActiveYou I.

Further considerations were needed as children with physical and intellectual/learning disabilities were both included in the target group. Due to different cognitive abilities, some children—even at the upper end of the age range—might have more difficulties than others answering the questionnaire. Therefore, simply making different versions of the instrument for different age groups would not solve this specific issue. Assistance would be needed. Furthermore, group interviews showed some differences regarding facilitators and barriers to participation. Children with physical disabilities often depended on specialized equipment and

adapted environments or had to deal with pain during participation (see article 2). Such aspects were not reported for children without physical disabilities. However, to account for facilitators and barriers in the complete target group, such aspects needed to be included in the instrument. This led to a higher number of response alternatives, which became especially challenging to deal with for children with learning disabilities, as cognitive interviews showed (see article 3).

In conclusion, even though an instrument designed for a wide target group might be needed for the context ActiveYou II is designed for and might make the instrument attractive for similar heterogeneous settings, the instrument becomes less optimal for individual subgroups within the large target group, or for very specialised settings.

### 5.2 Research with children

One of the main aspects of this thesis was research that included children and youth with disabilities as respondents. Although there has been made extensive consideration on how to include this vulnerable group in interviews, and how to adjust the methods for this group – as explained in chapter 3 – some aspects need further discussion. In this section, key learnings will be discussed. These can be differentiated into children as informants in interviews and children as respondents to questionnaires.

Generally, it can be said that including the children's perspective in the research was valuable. Therefore, this thesis can support the CRC and the Convention on the Rights of Persons with Disabilities in their demand to include children's voice to the best of one's abilities (Unicef, 1989; United Nations, 2006). The project showed how including the children's voices brought forward positions and aspects that otherwise might have been overlooked. Group interviews showed that the perspective of parents did not automatically reflect the perception of the children. A very clear example was the earlier mentioned example when a mother reported how her child enjoyed helping out on the farm they were living on; whereas the child—in a separate group interview with children—reported that they hated to do these duties on the farm. Such differences can only be identified by including the children's perspectives. Furthermore, as discussed in article 3, involving children in the developmental process through cognitive interviews brought forward the weaknesses of the instrument. These were mostly related to how questions were phrased and the terminologies used. Most of these aspects would most likely never been detected without asking the children directly. Adjustments after the cognitive interviews will help to enhance the quality of the instrument during the development process.

However, there have been challenges in this process that need to be addressed. The main one concerns recruitment of participants. One of the main issues of the project referred to problems in recruiting enough children to participate in the interviews. The main researcher (PhD scholar) invested time in informing both children and parents and spent several days participating with the children in their activities during their intensive intervention to build a positive relationship and trust. However, it was hard to motivate children to participate in the interviews. Even when agreeing to participate, children might change their mind at the last minute.

One strategy to enhance participation in interviews involved offering small incentives to the children participating (valued around 50 NOK/ 5 EUR). Heath et al. (2009) discussed the use of incentives. In their opinion, this strategy is gaining acceptance in the scientific community, but it may lead to a bias in the sample. During this project, it became apparent that children, especially under the age of 10 years, primarily participated in the interviews to get the incentives. This led to the case where children asked several times during the interviews, *'When do we get our bonus?'.* From the perspective of this thesis, future studies should spend more time in building a positive relationship and trust with the children – possibly over a period of one or several weeks – than relying on incentives. Furthermore, as children tended to change their mind about participating quite spontaneously, research should have been more flexible and spontaneous during the project. Instead of scheduling interviews several days or even a week beforehand, (not least because the researcher had to travel a considerable distance), it could have been an advantage if the interviews could be done on a more spontaneous basis. Possibly an approach, more often used in anthropology, with a combination of participating observation, supplemented with spontaneous interviews over a longer period, could be more productive. If the scholar could have followed several groups at the cooperating center during their three-week rehabilitation stay, this might have been beneficial. Since the scholar had worked at the center for several years and already was familiar with the staff and routines, this should have been feasible. In retrospect, it is assumed that results of the thesis might have been strengthened with methods like participating observation.

Another aspect of the interviews was the age of the participating children. According to Andersen and Dolva (2015), it is important that children are capable of reflecting on their experience. In their opinion, this could be the case for children age 8–14 years. Heath and colleagues (2009) argue that children age 8–11 years should be able to distinguish between different views, while children age 12–16 years should have even more abilities to reflect on

their experiences. According to Docherty and Sandelowski (1999), children at the age of 5 years might be able to participate in simple interviews researching their perspective on things. However, the research during this thesis found that interviews with children under the age of 10 years old was especially challenging. Even when asking open questions, children tended to answer in yes-no categories or with simple responses like *'I like it''* or *'It's fun.'* When further asking why things are fun, the children responded *'Because they are fun.'* It became apparent that the few children over the age of 10 years that participated in the group interviews were more reflective about their experiences and more capable of expressing these. In their guidelines, Lewis and Porter (2004) discuss that researchers should consider using different assets like pictures, drawings, diaries, videos or role play in interviews to enhance the narrative of the children.

In retrospect, asking children to bring some pictures or equipment from their favourite activities with them, or to draw a picture of their favourite activity/activities, could have enriched the children's responses and could have been used as an easier starting point to talk about their experiences in leisure activities. When doing cognitive interviews, the included children were exclusively older than 10 years (mean age 12.6 years). Compared with group interviews, where the majority of the participating children were below 10 years, participants in cognitive interviews were able to express their perspectives and opinions way better. Therefore, based on the research in this thesis, the age of the children should be considered carefully and depend on the aim of the interviews.

Another important part of the thesis that involved children as respondents was the survey. Since the aim of this thesis was about development of a self-reported questionnaire for children and youth with disabilities, appropriate use of this method was of special value here. As explained in the methods chapter, designing questionnaires suitable for children to respond to comes with several challenges, the biggest being that the instrument should fit children and youth age 5–17 years. In group interviews with professionals, this was pointed out specifically. Based on his experience with other instruments, one physician argued:

> *I still think that the huge age span will be a challenge, since . . . well . . . I know other instruments. With these you usually have three different age groups. [. . . ] You have to expect that [the]activity interests of a 17-year-old differ from a 6-year-old. [. . .] I don't really see how to combine them in one questionnaire.*

Research on participation in leisure activities in Norway has shown that besides staples like cross-country skiing, swimming, outdoor activities and football, activities like visiting fitness centres become relevant for children age 14 years and older (Statistics Norway, 2015). Therefore, the instrument should apply a similar set of activities for all age groups. However, as Hoberg and Nyquist (2011) found when testing CAPE and PAC with each 55 activities, children had difficulties concentrating over a long period to complete the questionnaire. Therefore, ActiveYou II focuses primarily on physical leisure activities to reduce the number of activities included.

A more important issue is assuring the applicability of the questionnaire to all age groups. As Heath et al. (2009) explain, there are considerable differences in concentration span, language and reading abilities, depending on the age of the respondent. To assure appropriate formulations and applicability, cognitive interviews were included in the project. Furthermore, in group interviews participants were asked about what they wished for in a self-reported questionnaire for children. As most parents and children already had experienced answering ActiveYou I (Dalen, 2019) or other questionnaires, they argued based on what they experienced as positive or negative features with these. Key points were:

- As few questions per page as possible
- As little text as possible
- Applying a three-point smiley scale (standard Likert-type scales are too difficult, differentiating into a five-point scale)
- Illustrating the activities with one or multiple pictures

These important key points have been adapted to ActiveYou II. To evaluate further how many children are in need of assistance, future cognitive interviews and test periods should include a question about whether the child answered the questionnaire independently or needed/sought help.

Using online research is expected to work well for the target population. Parents in group interviews reported (based on their experience with ActiveYou I) that children – especially those with cerebral palsy – often had poor fine-motor skills. Being able to answer a questionnaire digitally, using a mouse or touch-screen technology, worked far better for them than the traditional paper-and-pencil questionnaires they knew from before. Additionally, pictures or small slide shows helped to illustrate the activities for the children. This led to the

conclusion that online questionnaires may be the preferable administration mode for this group of children.

### 5.3 Reflections the participation-construct within the ICF

Developing an instrument on participation does automatically include an intensive confrontation with the concept of participation itself. Within healthcare and rehabilitation, the 'International Classification of Function, Disability, and Health' (World Health Organisation, 2001) is designed as a framework for research and clinical work in healthcare and rehabilitation (Hemmingsson & Jonsson, 2005; Maxwell et al., 2012). As discussed at the beginning of this thesis, the conceptualisation and definition of participation within the ICF have received many critiques, mainly for its lack of clarity and lack of subjective perspective like experience on participation. This thesis has worked both on theory building – via a scoping review on the concepts of involvement and engagement – and intensively collecting data on the subjective perspective on participation, doing group interviews. It is thus of interest how this research must be reflected in relation to the discussion around the conceptualisation of participation within the ICF, especially concerning the individual perception/perspective and definition of these individual aspects.

On a theoretical level, the scoping review supports the argument about the lack of clarity in the terminology of the ICF. The ICF defines participation as *'involvement in life situation'* (World Health Organisation, 2001, p. 10), but it lacks a definition of involvement, aside from an unclear footnote. The scoping review found no use of that the concept of involvement, as used in the ICF within healthcare and rehabilitation. In other fields of research – specifically consumer and leisure research – involvement describes the interest or motivation towards an activity or associated product.

An argument can be made that purely being interested in a life situation does not qualify as participation. The practical manual for the ICF states that participation *'always entails the execution of an action or task'* (World Health Organisation, 2013, p. 22). This condition would refer to the engagement in an activity. If one argues that taking part in a life situation and feeling a sense of belonging is part of participation – as can be interpreted by the vague footnote on involvement in the ICF – then most research would refer to the concept of engagement (see Article 1).

In this concept, the scoping review showed a consensus over the fields of (human resource) management, educational psychology, and, more recently, healthcare and rehabilitation. In all

three fields, behavioural engagement is about attendance, time on task or frequency of attendance; cognitive engagement includes the individual's goalsetting and reasoning for participation, and affective engagement, the emotional connection to other participants – that is, the sense of belonging. Therefore, if one wants to remodel the ICF – like Mitra and Shakespeare (2019) argue for – one could start by rephrasing the definition of participation into *'engagement in life situation'* and provide an accompanying definition of engagement: *'The individual's behavioural, cognitive and affective investment during role performance'*. However, this would be an expansion, or supplementation, rather than a remodelling.

Regarding the critique on the lack of the individual's perspective and experience of participation within the ICF, group interviews may be a source of data in this thesis that can contribute to this discussion. During the group interviews, parents and professionals were asked about their understanding of participation. Most participants argued in the sense of *'feeling included'*, *'partake with others on an equal level'*, or *'being part of a social group'*. This general understanding of participation – as reported by the participants in this thesis – highly valued the subjective participation experience over purely observable aspects of participation. Research tends to focus on the observable aspects, like attendance, frequency of attendance, time on task or performance, and lack the subjective experience of participation (B. Adair et al., 2018). In contrast, parents shared stories of their disabled child being the 'water boy' or 'assistant team manager' in a football or handball club and experienced this as participation. Moreover, oftentimes – depending on the attitude of their peers – they felt like an equal member of the team.

Observing these children in their participation – following a protocol, checking boxes for time on task or performance – would possibly conclude the observation with the statement that the children do not participate. The same would be the case when trying to measure participation in physical leisure activities using an accelerometer, heart rate monitors, or activity watches. Therefore, a conceptualisation of participation that lacks the individual's perspective might not give a holistic description of the phenomenon. This leads to the necessity of including these aspects of participation in the ICF. In 2013, the World Health Organisation (2013, p. 24) also stated that they consider *'develop[ing] a "qualifier for involvement or subjective satisfaction" for the activities and participation component'*. Therefore, this thesis would like to support the argument for an extension with another subjective qualifier, as argued by Granlund et al. (2012).

# 6

## 6. Conclusion

This thesis aimed to develop a new Norwegian, self-reported, web-based measure of physical leisure activities for children and youth with disabilities through theory work and a multistep developmental process. A first version of ActiveYou II could be developed, though the instrument is not ready for clinical use. Psychometric testing for qualitative properties of the instrument is the next step. This testing includes a test-retest approach for reliability and measurement error, as well as additional cognitive interviews with the target group and expert panels to assure content validity.

Besides measure development, this thesis discussed relevant topics within participation research. These topics incorporated the direct perspective of the children into the research, which was perceived as valuable and should be addressed even more in future research. The thesis also delved into the discussion about the participation construct within the ICF framework. Based on theory work and data collection within the project, the critique on the conceptualisation of participation within the ICF by several researchers in healthcare and rehabilitation is supported by this study. An extension of the current framework in the ICF regarding the individual perspective in the conceptualisation of participation is needed.

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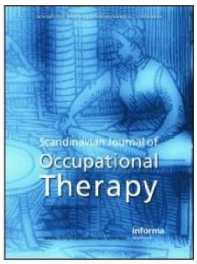
## Articles

Article 1



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# Exploring two subdimensions of participation, involvement and engagement: A scoping review

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REVIEW ARTICLE

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# Exploring two subdimensions of participation, involvement and engagement: A scoping review

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**ABSTRACT**

**Background:** The conceptualisation of participation is an ongoing discussion with importance for measurement purposes. The aim of this study was to explore the two subjective subdimensions of participation, *involvement* and *engagement*. The purpose was related to measure development within the field of paediatric rehabilitation.

**Methods:** In a scoping review, following the PRISMA-ScR, the databases *MEDLINE, PubMed, Academic Research Complete, PsychINFO,* and *Business Source Complete* were searched for publications that described engagement and/or involvement constructs.

**Results:** Thirty-nine publications met the inclusion criteria. *Involvement* could be conceptualised as an unobservable state of motivation, arousal, or interest towards a specific activity or product. Building a consensus over different fields of research, *engagement* can be seen as the individual's behavioural, cognitive and affective investment during role performance.

**Conclusions:** This scoping review points in a direction that the two subdimensions of participation need to be separated, with involvement being a more stable internal state of interest towards an activity, and engagement referring to the specific behaviour, emotions, and thoughts meanwhile participating in a specific setting. Clear definition of concepts will enhance the development of measures to evaluate rehabilitation interventions in the field of occupational therapy and related fields.

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Children and youth; disability; participation; physical activity; rehabilitation

## Introduction

Optimising participation is one of the main goals in modern healthcare and rehabilitation, particularly for children and adolescents with disabilities [1–6]. Participation is described as a primary outcome in paediatric rehabilitation [7], but it lacks a clear and overall accepted definition. For example, involvement and engagement are subjective subdimensions of participation that are often used interchangeably and thus far have often have been neglected in measuring participation [8]. For measuring purposes clear definitions are needed. In paediatric rehabilitation, it is considered preferable to apply self-reporting when measuring childrens' participation, as child-reported measures support person-centred and value-based care in line with international conventions on the rights of children and persons with disabilities [9,10]. Adair et al. [8] argue that, to measure subjective or internal aspects of participation, it is important to have the individual as a direct informant. Thus far, self-reported instruments that include the individual aspects of participation are rare and, and thus limiting the evaluation, especially of the subjective perspectives of participation [8]. When measuring participation, concepts and constructs need to be clearly defined. The aim of this study was to explore the two subjective subdimensions of participation, involvement and engagement. The purpose was to identify definitions of the two constructs to be used in measure development, regarding activity participation in children and youth with disabilities.

Following the Oxford dictionary [11] participation is defined as '*the action of taking part in something*'. Involvement is defined as '*the fact or condition of being involved with or participating in something*'. Engagement is defined as '*an arrangement to do something or go somewhere at a fixed time*' in the context of the activity.

In the World Health Organisation (WHO)'s 'International Classification of Functioning, Disability,

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and Health' (ICF) – the conceptual foundation of healthcare and rehabilitation practice – participation is defined as '*involvement in life situations*'. The WHO does not give a clear definition of the term, besides one single footnote '"*involvement*" *incorporates taking part, being included or engaged in an area of life, being accepted, or having access to needed resources*' [12,p.13]. The ICF has been criticised for its lack of conceptual clarity and for not including the individual's perspectives on their participation [1,13–15]. Moreover, the conceptual issues contribute to difficulty in trying to measure participation. Both activity and participation are represented as covering the same nine life areas in ICF, representing aspects of functioning from an individual (activity) and societal (participation) perspective [16]. The distinction between the participation and activity dimensions in the ICF is complex, but it is argued that participation is more determined by environmental and cultural factors, whereas activity tends to be more distinct and limited by body impairments [16–18]. Granlund et al. [19] argue that environmental factors in the ICF are mainly based on the social model of disability, with society shaping the physical environment and civil rights but lacking the subjective experience.

There are multiple other models of participation. In the context of participation for children and youth with disabilities, the '*Family of Participation Related Constructs' model* (fPRC-model) [7] is a more recently developed framework that derived from literature on health, disability, psychology, and education. In the fPRC-model participation is defined as attendance and involvement [7]. The fPRC-model defines involvement as '*the experience of participation while attending, that may include elements of engagement, motivation, persistence, social connection, and affect*' [7,p.18], and engagement as '*a unifying construct across ecological levels. Thus, it can be defined depending on the ecological level in which it is examined: (1) the person level – the internal state of individuals' involving focus or effort; (2) between systems level – an active involvement in interactions between systems; (3) at the macro level – active involvement in a democratic society*' [7,p.20].

Neither the ICF nor the fPRC-model clearly distinguish between, or unify, the two subdimensions. As Granlund et al. discuss [19], the ICF could benefit from another subjective qualifier of participation, since the qualifiers of performance and capacity cannot capture the subjective experience of participation. Furthermore, no consensus can be found between the Oxford dictionary, the ICF, and the fPRC-model. Thus, it remains unclear whether both terms are identical or whether there are distinctions to be made.

Clear definitions are a necessity when measuring participation and the subdimensions, involvement and/or engagement [20–24]. Therefore, an enhanced understanding of both subconstructs is required; to attain this understanding. As research on the subjective subdimansions of participation is scarce, occupational therapists and related healthcare professions may benefit from looking into other and related fields of research for definitions.

The aim of this study was to explore the two subjective subdimensions ofthe participation construct. The research questions were: (i) What definitions of engagement and involvement – applicable for measure development – can be found within different fields of research? (ii) Can the subdimensions of participation, involvement and engagement, be used interchangeably or do they need to be differentiated?

## Method

A scoping review method was chosen to broadly explore the conceptualisation of involvement and engagement. This method – a type of knowledge synthesis – aims to start a research process, discover knowledge gaps to be developed in future research [25,26]. The research process followed the PRISMA-ScR guidelines [27]. The main database search took place during May/June 2018, and an update search followed in October 2020. The purpose was to cover fields in which engagement and involvement already have been defined and included in measures. These definitions might be transfereable into healthcare and rehabilitation. Several databases were included in the search process: *MEDLINE, PubMed, Academic Research Complete, PsychINFO,* and *Business Source Complete*. These databases were chosen through a discussion with researchers experienced in structured literature reviews in diffenrent databases and fields of research. The search was based on preparatory literature search of the terms '*involvement construct*' and '*engagement construct*' using *Google Scholar*. The search showed that research on involvement was quite pronounced in the fields of consumer and leisure research. Since it was important to get an increased knowledge of the constructs, these fields were added representing by the databases Academic Research Complete, PsychINFO (leisure research) and Business Source Complete (consumer research). For engagement, the research seemed to be most distinctive in economics and management, as well as in educational

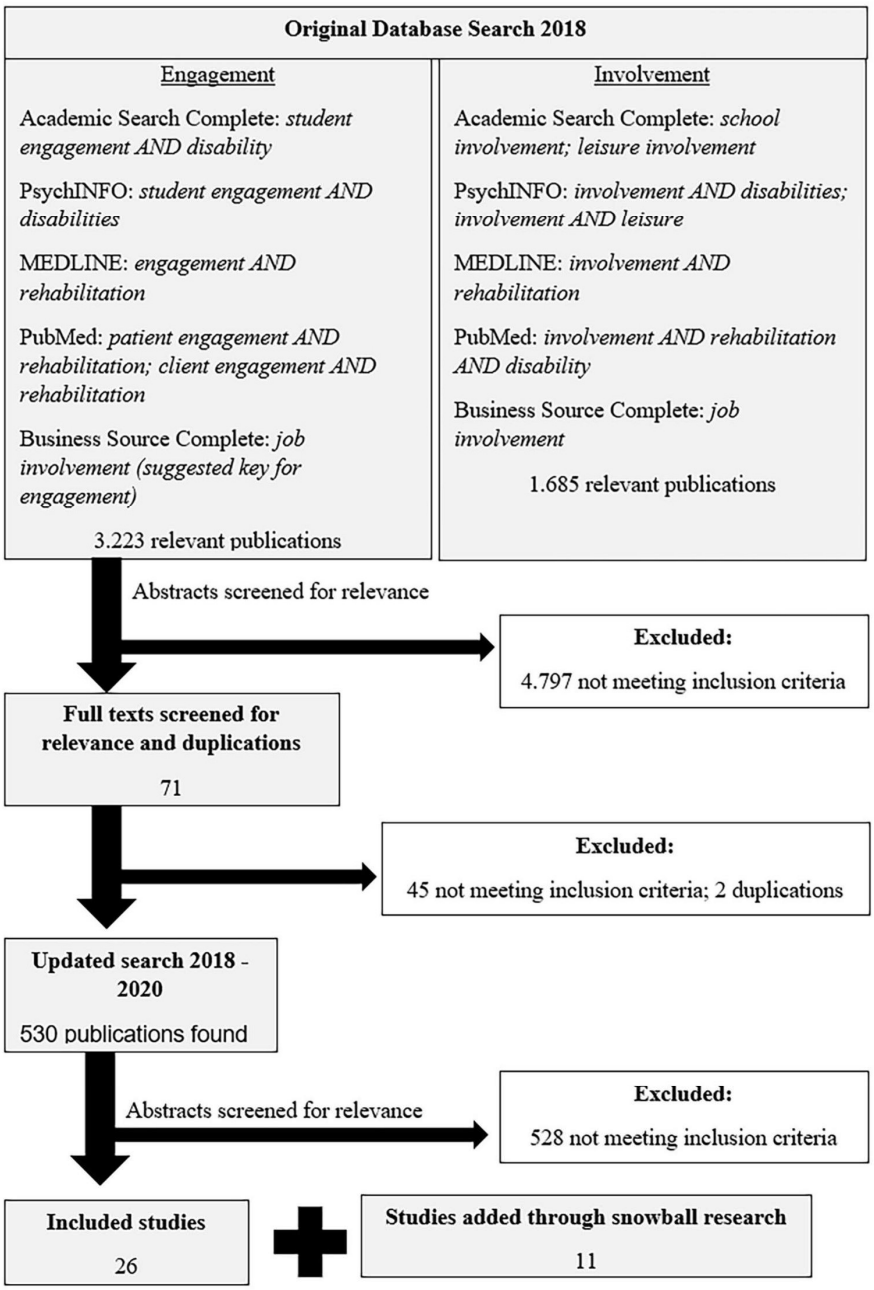


**Figure 1.** Flowchart of the search process.

psychology covered by the databases; *Business Source Complete (economics), PsychINFO and Academic Research complete (educational psychology).* Since the purpose of the study was to gain an understanding of these constructs for application in the field of healthcare and rehabilitation, medical databases *MEDLINE* and *PubMed,* were added to the research process as well.

Figure 1 and Table 1 give an overview of the process of the literature search. Inclusion criteria for publications were: published in English; peer-reviewed; publication defines the 'involvement' and/or 'engagement' construct; type of publication: theoretical/conceptual article, or instrument development, or review. The inclusion criteria 'published in English' and 'peer-reviewed' were applied as filters in the

**Table 1.** Detailed overview of database search.

| Search-term/key words | Databases | Results | Used filter | Results with filter | Relevant abstracts | Relevant fulltext |
|---|---|---|---|---|---|---|
| Patient engagement | PubMed | 51,011 | Keywords added | | | |
| Patient engagement AND rehabilitation | PubMed | 7665 | Child 0–18 years | 1054 | 19 | 2 |
| Updated search 2018–2020 | PubMed | 29 | Child 0–18 years | – | – | – |
| Client engagement | PubMed | 9153 | Index words added | | | |
| Client engagement AND rehabilitation | PubMed | 1196 | | 1196 | 11 | 5 |
| Updated search 2018–2020 | PubMed | – | | – | – | – |
| Engagement | MEDLINE | 4386 | Index words added | | | |
| Engagement AND Rehabilitation | MEDLINE | 11 | – | – | 2 | 1 |
| Updated search 2018–2020 | MEDLINE | 18 | – | – | 1 | 1 |
| Student engagement | Academic Search Complete | 2443 | Index words added | | | |
| Student engagement AND disability | Academic Search Complete | 53 | – | – | 3 | 2 |
| Updated search 2018–2020 | Academic Search Complete | 12 | – | – | – | – |
| Student engagement | PsychINFO | 3124 | Index words added | | | |
| Student engagement AND disabilities | PsychINFO | 54 | – | – | 2 | 2 |
| Updated search 2018–2020 | PsychINFO | 11 | – | – | 1 | – |
| Job involvement (suggested as key word for engagement) | Business Source Complete | 855 | – | – | 16 | 7 |
| Updated search 2018–2020 | Business Source Complete | 17 | – | – | – | – |
| School | Academic Search Complete | 238 | – | – | 2 | 1 |
| Involvement | | | | | | *(Transferred to engagement)* |
| Updated search 2018–2020 | Academic Search Complete | 89 | – | – | – | – |
| Leisure involvement | Academic Search Complete | 716 | – | – | 9 | 4 |
| Updated search 2018–2020 | Academic Search Complete | 121 | – | – | 1 | 1 |
| Involvement | PsychINFO | 11,820 | Index words added | | | |
| Involvement AND disabilities | PsychINFO | 213 | – | – | 3 | 0 |
| Updated search 2018–2020 | PsychINFO | 34 | – | – | – | – |
| Involvement AND leisure | PsychINFO | 160 | – | – | 4 | 2 |
| Updated search 2018–2020 | PsychINFO | 18 | – | – | – | – |
| Involvement | MEDLINE | 333,843 | Index words added | | | |
| Involvement AND rehabilitation | MEDLINE | 117 | – | – | – | – |
| Updated search 2018–2020 | MEDLINE | 7 | – | – | – | – |
| Involvement | PubMed | 373,987 | Index words added | | | |
| Involvement AND rehabilitation | PubMed | 7491 | Index words added | | | |
| Involvement AND rehabilitation AND disability | PubMed | 1881 | – | – | – | – |
| Updated search 2018–2020 | PubMed | 174 | – | – | – | – |
| Duplications of fulltexts from database researches | | | | | | − 2 |
| Total number of studies included from database researches | | | | | | 26 |
| Publications added through snowball research | | | | | | |
| Engagement | | | | | | 7 |
| Involvement | | | | | | 4 |
| Total number of studies included from snowball research | | | | | | 11 |
| Total number of studies included | | | | | | 37 |

initial search in each database. Using only the index words 'involvement' or 'engagement', the literature search would be too broad and results would not have been manageable in the frame of this scoping review.

In order to narrow the literature search, additional index words were added. These were based on keywords used by publications found in the initial search on Google-Scholar and the indexed subject headings or controlled terms from a thesaurus/register of each individual database. Since the purpose of the scoping review was related to the field of disability and rehabilitation, the index word '*rehabilitation*' was added when searching medical databases (MEDLINE and PubMed). For databases within social sciences, the indexed word 'disability' *or* 'disabilities' (depending on the index word register of each database) was added. The initial search on '*involvement construct*' showed high relevance in the field of leisure research, thus '*leisure*' was used as an additional index word for the involvement construct. Several databases did not include the terms '*involvement*' and '*engagement*' as individual index words. In these cases, the suggestions of the individual databases were adapted (see Figure 1; Table 1). For example, the database PubMed did not include '*engagement*' as an individual and index word. Instead, the database suggested '*patient engagement*' and '*client engagement*'. Because a search on '*patient engagement*' produced 51,011 results, the search was narrowed using the filter 'age: child 0–18 years'. Another index word – '*rehabilitation*' – was added, and as the search still produced 7286 results, a filter (age: child 0–18 years) was added to narrow the search.

In addition – using snowball search – publications that were frequently referred to were added to the search process. The snowball method is a way of finding literature by consulting the bibliography in the key document to find other relevant titles. This strategy ensured the inclusion of articles that might have been excluded due to additionally used index words, or due to different indexing of the articles.

The main search resulted in 3223 publications available for 'engagement' and 1685 for 'involvement'. After screening the titles and abstracts in relation to the inclusion criteria, 71 studies met the inclusion criteria. After excluding duplications (two), the remaining 69 articles were followed up by reading the full texts. Of these, 45 articles did not specifically define the constructs of involvement or engagement. Eventually, 24 publications matched all the inclusion criteria, and were judged resourceful as a basis for a scoping review. The first researcher performed the screening and selection of the articles independently. In the updated search in 2020 – using the same databases and search-terms – another 530 publications were found (87 for engagement; 443 for involvement). After the screening for relevance two additional full-texts were added to the review.

The snowball search resulted in another 11 publications. Thus a total of 37 publications were included in the study (10 for involvement, 27 for engagement). Data extraction was done manually and followed the methodological framework for scoping reviews proposed by Arksey and O'Malley [25]. Data were charted, including information about the author, year of publication, study location, type of study, and researched population. Furthermore, the included publications were screened for definitions and any measures used to capture the constructs of involvement and/or engagement. Charting further included key components of the understanding of the involvement or engagement construct (see Tables 2 and 3).

## Results

### *Involvement*

Ten publications were found regarding the construct of involvement. These were from the fields of sports management [28], consumer research [21,29], and leisure research [30–36]. Due to similarities in the populations and settings being researched, the publication in sports-management [28] was considered alongside the publications in leisure research. Even though the WHO has defined 'involvement' as being central to the definition of participation, no further explanation of the construct could be identified in the included articles, besides the earlier-mentioned footnote in ICF.

### *Consumer research*

Consumer research views involvement primarily as the '*perceived importance of a product*' [29,p.43], or '*a person's perceived relevance of the object based on inherent needs, values, and interests*' [21,p.342]. To evaluate consumer involvement, measures like the '*Personal Involvement Inventory*' (PII) [21] and the '*Customer Involvement Profiles*' (CIP) [29] have been developed. The questionnaires originally were meant to capture consumer perceptions of personal relevance relating to several consumer goods [33].

**Table 2.** Publications included in the involvement construct (* publications added through snowball research).

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on involvement construct;<br>used/developed measures |
|---|---|---|---|---|---|
| Zaichkowsky*<br>1985<br>USA<br>[21] | Marketing | Instrument development | 268 undergraduate psychology students<br><br>49 MBA students<br><br>57 clerical and administrative staff members | A persons perceived relevance of the object based on inherent needs, values, and interests | Specific measures:<br>• developed instrument: Personal Involvement Inventory (PII)<br>• instrument was testes for validity and reliability<br>• PII is sensitive to different situations if people and product remain constant |
| Laurent and Kapferer*<br>1985<br>USA<br>[29] | Marketing | Instrument development | Face-to-face interviews with 207 housewives | Perceived importance of a product | Specific measures:<br>• developed instrument: 'Consumer Involvement Profiles' (CIP) scale<br><br>About the involvement construct:<br>• based on social judgement theory<br>• antecedents of involvement: perceived importance of product or situation; perceived sign value; perceived pleasure; perceived risk<br>• different facets of involvement have different influences on consumer behaviour |
| Havitz and Dimanche*<br>1997<br>USA<br>[30] | Leisure Research | Theoretical article | | Involvement has been defined as an unobservable state of motivation, arousal or interest towards a recreational activity or associated product. It is evoked by a particular stimulus or situation and has drive properties (adapted from Rothschild, 1984). | About the involvement construct:<br>• leisure involvement refers to how one thinks about leisure and recreation<br>• four facets: importance, pleasure, sign, and centrality to lifestyle facet best represent enduring leisure involvement<br>• involvement affects one's behaviour<br><br>On measuring involvement:<br>• measures often 'borrowed' from consumer research → all instruments has its strength and weaknesses<br>• advices for multifaceted instruments since they provide more information than unidimensional instruments |
| Wiley et al.<br>2000<br>Canada<br>[31] | Leisure Research | Theoretical article | 205 hockey players and figure skaters | defined involvement as a 'psychological state of motivation, arousal, or interest between an individual and an activity or product'. | About the involvement construct:<br>• locates involvement theory within social judgement theory<br>• applied to sports and leisure in the 1970s from consumer research<br>• see three facets of involvement: attraction, self-expression, and centrality<br>• in sports: attraction seems to be more relevant for women, while centrality seems to be more relevant to men<br>• incorporating involvement into the study of leisure has the potential to generate new |

(*continued*)

**Table 2.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on involvement construct;<br>used/developed measures |
|---|---|---|---|---|---|
| | | | | | understandings → assist in explaining particular aspects of leisure behaviour and leisure practice |
| Funk and James*<br>2001<br>USA<br>[28] | Sport Management | Theoretical article | | Involvement is defined as a 'state of motivation, arousal or interest towards a recreational activity or associated product' | About the involvement construct:<br>• set within the 'Psychological Continuum Model' (PCM)<br>• five facets of involvement: attraction, sign, centrality to lifestyle, risk probability, risk consequence |
| Funk, Ridinger and Moorman<br>2004<br>USA<br>[32] | Leisure Research | Theoretical article<br>Instrument development | Focus group interviews with spectators of women's basketball<br><br>SII pilot-test $n = 73$ women's basketball spectators → main study $n = 623$ | Leisure involvement has been defined as an unobservable state of motivation, arousal, or interest towards a recreational activity or associated product that is evoked by a particular stimulus or situation that possesses drive properties<br><br>sport involvement was defined as a psychological state of motivation, arousal, or interest in a team and related activities that is evoked by individual characteristics and situational factors that possess drive properties | Specific measures:<br>• developed instrument: Sport Involvement Inventory (SII)<br>• SII provided a psychometrically sound basis for involvement<br>• instrument incorporated in the 'team sport involvement' (TSI) model<br><br>About the involvement construct:<br>• involvement initially comes from research in psychology and social judgement theory<br>• four facets of involvement: attraction, self-expression, centrality to lifestyle, and risk<br>• aim of leisure involvement research to understand antecedents and behavioural consequences for participation in recreational activities and hobbies |
| Kyle et al.<br>2007<br>USA<br>[33] | Leisure Research | Instrument development | 424 campers in Sumter National Forest<br><br>430 consumers enquiring about angling opportunities in Santee Cooper Country | Involvement is said to reflect the degree to which people devote themselves to an activity or associated product. … Additionally, involvement refers to the strength or extent of the cognitive linkage between the self and stimulus object | Specific measures:<br>• tested instrument: Modified involvement Scale (MIS)<br>• MIS is psychometrically sound<br>• solid support for conceptualisation and measure of enduring leisure involvement<br><br>About the involvement construct:<br>• involvement consists of five dimensions: attraction, centrality, social bonding, identity affirmation, and identity expression.<br>• enduring leisure involvement is best conceptualised as a multidimensional construct |
| Jun et al.<br>2012<br>USA/Greece/ Australia<br>[34] | Leisure Research | Theoretical article | 424 recreationists in Sumter National Forest (USA)<br><br>260 participants in exercise in health centres (Greece) | Havitz and Dimanche's [30] often-used definition states that involvement is an ' . . . unobservable state of motivation, arousal or interest towards a recreational activity or associated product, evoked by a | About the involvement construct:<br>• five facets of enduring involvement: attraction, centrality, social bonding, identity affirmation and identity expression<br><br>specific measures: |

(*continued*)

**Table 2.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on involvement construct; used/developed measures |
|---|---|---|---|---|---|
| | | | | particular stimulus or situation, and which has drive properties' | • used instrument: Modified Involvement Scale (MIS; Kyle et al. [33])<br>• measures may shift from context to context to account for subtleties within populations and activities |
| Havitz, Kaczynski and Mannell<br>2013<br>USA/Canada<br>[35] | Leisure Research | Theoretical article | 384 adults | defined by Havitz and Dimanche [30] as an 'unobservable state of motivation, arousal or interest towards a recreational activity or associated product, evoked by a particular stimulus or situation, and which has drive properties' | Specific measures:<br>• used instrument: Modified involvement Scale (MIS)<br><br>About the involvement construct:<br>• leisure involvement has demonstrated influences on various types of leisure behaviour, yet has received only limited attention in the physical activity literature<br>• five dimensions of leisure involvement: attraction, centrality,<br><br>identity expression, identity affirmation, social bonding<br>• leisure involvement has together with self-efficacy and motivation strong influence on behaviour |
| Surhartanto et al.<br>2019<br>Indonesia<br>[36] | Leisure research/tourism | Theoretical article | 313 adults | Refer to different definitions of involvement, starting with Havitz and Dimanche [32] | Abaout the construct<br>• consensus that involvement is a multi-dimensional construct<br>• depending on literature between three and 5 key-dimensions<br>• most important dimensions: importance, centrality, and self-expression |

**Table 3.** Publications included in the Engagement construct (* publications added through snowball research).

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| Kahn*<br>1990<br>USA<br>[40] | Economics/<br>Management | Conceptual article | | Personal engagement: 'harnessing of organisation members' selves to their work roles; in engagement, people employ and express themselves physically, cognitively, and emotionally during role performances' | About the engagement construct:<br>• focuses on the work-setting<br>• personal engagement has a physical, cognitive and emotional component<br>• personal engagement is an outcome of job-involvement |
| Fredricks, Blumenfeld and Paris*<br>2004<br>USA<br>[50] | Educational<br>Psychology | Review | | A meta-construct that includes behavioural, emotional and cognitive engagement<br>Behavioural (i.e. time on task)<br>Emotional (i.e. interest and value)<br>Cognitive (i.e. self-regulation and learning strategies) | About the engagement construct:<br>• engagement can be thought of as a 'meta' construct<br>• engagement literature is marked by duplication of concepts and lack of differentiation in definitions across various types of engagement<br>• engagement is multidimensional: behavioural, academic, emotional, and cognitive<br>• engagement-construct has the potential to link areas of research about antecedents and consequences of students behaviour, emotions, and thought process<br>• engagement-construct is inclusive: it combines constructs that usually are researched separately<br>• research has yet not capitalised on the potential of the construct |
| Appleton et al.*<br>2006<br>USA<br>[45] | Educational<br>Psychology | Instrument<br>Development<br>(validation) | Ninth-graders<br>($N = 1938$) | Engagement is viewed as a multi-dimensional construct comprised of four subtypes: academic, behavioural, cognitive, and psychological.<br>Other definitions quoted in main-text:<br>Energy in action, the connection between person and<br>activity<br>Reflects a person's active involvement in a task or activity | Specific measures:<br>• instrument: Student Engagement Instrument (SEI) – measuring the students level of cognitive and affective engagement in theri school setting<br>• statistical support for the validity of the SEI was found in numerous ways<br>• model extends the engagement literature by providing empirical support for a self-reporting scale that includes unobservable aspects of engagement<br><br>About the engagement construct:<br>• behavioural and academic engagement as observable components, that more easily can be quantified<br>• cognitive and psychological engagement includes less observable, more internal indicators<br><br>on measuring engagement:<br>• research thus far has focussed on observable components<br>• focus on emotional/cognitive components of engagement crucial to better understand education outcome<br>Specific measures: |

(*continued*)

**Table 3.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| Kortte et al.<br>2007<br>USA<br>[60] | Healthcare and rehabilitation | Instrument development | 206 patients with different physical and cognitive impairments | Engagement in rehabilitation therapy may be defined as an interest in, and an intentional effort to, work towards the rehabilitation goals.<br>Rehabilitation engagement is conceptualised as a construct that captures multiple elements, including a patient's attitude towards the therapy, his/her level of understanding or acknowledgment of a need for treatment, the need for verbal or physical prompts to participate, the level of active participation in therapy activities, and the level of attendance throughout the rehabilitation program. | • Hopkins Rehabilitation Engagement Rating Scale (HRERS). Questionnaire for therapists<br>• HRERS is reliable and valid<br>• instrument measures aspects of the rehabilitation process that relate to short- and long-term outcomes<br>• HRERS is useful for measuring engagement as part of the medical rehabilitation process |
| Appleton, Christenson and Furlong*<br>2008<br>USA<br>[44] | Educational psychology | Review | | Energy in action, the connection between person and activity<br>Engagement reflects a person's active involvement in a task or activity | About the engagement construct:<br>• all definitions for student engagement include behavioural components – many also contained emotional/psychological components<br>• far fewer conceptualisations include academic or cognitive components in their definition<br>• necessary to move beyond indicators of academic and behavioural engagement to understanding the underlying cognitive and psychological needs of all students<br>• knowledge of more cognitive and psychological subtypes of student engagement may enhance effective interventions<br>• researchers need to clearly define their conceptualisation in each study |
| Duchan 2009<br>USA<br>[52] | Psychology | Discourse analysis | | Engagement has been employed in different literatures to describe the feelings one has about a relationship or about the activity taking place | About the engagement construct:<br>• both engagement and involvement can be used to describe a person's avid and active connection with another person<br>• engagement portrays degrees of involvement |
| Axelson and Flick<br>2010<br>USA<br>[48] | Educational psychology | Conceptual article | | Quote Astin's definition of student involvement for student engagement: 'the quantity and quality of physical and psychological energy that students invest in the college experience' | About the engagement construct:<br>• Alexander Astin's student involvement research in the 1980s builds foundation for what would eventually become modern engagement research<br>• not all educational theorists agree that involvement and engagement are the same thing<br>• engagement is seen primarily in emotional, cognitive, or behavioural terms or as a meta concept<br>• modern definitions of the construct often confusing both semantically and conceptually |
| Lequerica and Kortte<br>2010 | Healthcare and rehabilitation | Conceptual article | | The concept of 'engagement in rehabilitation' is operationally defined here as a deliberate | About the engagement construct: |

(*continued*)

**Table 3.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| USA<br>[61] | | | | effort and commitment to working towards the goals of rehabilitation interventions, typically demonstrated through active, effortful participation in therapies and cooperation with treatment providers | • engagement as one construct that incorporates several rehabilitation process elements<br>• engagement critical for patients fully benefiting from medical rehabilitation interventions<br>• engagement is differentiated from participation as a separate but related construct → participation signifies the behavioural component of engagement, it does not necessarily require high levels of invested interest<br>• motivation and engagement as two related but distinct constructs → motivation is energy directed in a particular way vs. engagement is that energy put into action<br>• therapeutic engagement as a primarily cognitive model of engagement |
| Finn and Zimmer*<br>2012<br>USA<br>[49] | Educational psychology | review | | Define sub-components:<br>Academic (behavioural): observable behaviours related directly to the learning process<br>Social (behavioural): the extent to which a student follows written and unwritten classroom rules of behaviour<br>Cognitive (behavioural internal): the expenditure of thoughtful energy needed to comprehend complex ideas in order to go beyond the minimal requirements<br>Affective: emotional response characterised by feelings of involvement in school as a place and a set of activities worth pursuing | About the engagement construct:<br>• early definition of engagement: 'the student's psychological investment in and effort directed towards learning, under-standing, or mastering the knowledge, skills, or crafts that academic work is intended to promote'<br>• newer models with three, four or more components: academic, social, cognitive, affective<br>• still no clarity on the definition of the construct |
| Liem and Martin*<br>2012<br>Australia<br>[54] | Educational psychology | Instrument development | Collection of multiple studies/samples | Motivation is defined as individuals' energy and drive to learn, work effectively and achieve to their potential, and engagement as the behaviours aligned with this energy and drive | Specific measures:<br>• developed instrument: Motivation and Engagement Scale (MES), measuring the students motivation, cognitive and affective engagement, as well as his perception for himself as a studnet<br>• MES-High School (MES-HS) has strong psychometric properties<br>• MES-HS is sensitive to detecting changes in students' motivation and engagement after motivation and engagement intervention.<br>• MES-Work (MES-W), MES-Music (MES-M), and MES-Sport (MES-S) – have been developed<br>• MES-S has been validated with sub-elite young athletes at a specialist sports high school<br><br>About the engagement construct:<br>• Motivation and Engagement Wheel was developed as a multidimensional framework |

(*continued*)

**Table 3.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| | | | | | representing salient cognition and behaviour pertinent to motivation and engagement |
| Kemp et al.<br>2013<br>Australia<br>[53] | Educational psychology | Study on engagement of young children with disabilities in childcare settings | Young children with disabilities ($n = 37$; age 13 – 36 month) | Child engagement was defined as 'situationally appropriate interactions with the physical environment, materials, or other persons' | Specific measures<br>• measure used: ICERR, which has been previously field tested and validated |
| Alegria et al.<br>2014<br>USA<br>[56] | Medicine | Clinical Trial/ Intervention Study | 722 patients (18–70 years) | Engagement was defined as the proportion of behavioural health visits attended of those scheduled in the 6 months after the baseline assessment, | Specific measures<br>• medical records review or by querying electronic health records |
| Bhuvanaiah and Raya<br>2014<br>India<br>[37] | Management | Review | | Engagement is a degree, which exists to certain extent. During the process of engagement, employee gets motivated either of self-motivation or by external motivation which drives employee to be energised to perform a task.<br>Employee engagement is said to be so called 'energy' utilised in accomplishing purpose. | About the engagement construct:<br>• even though engagement is a well-researched construct, it lacks a universally acceptable definition that distinguishes employee engagement from other relative constructs<br>• researchers defined the concept in the view of individual perspective or organisational perspective in relation to the purpose of their study |
| King, Currie and Peterson*<br>2014<br>Canada<br>[24] | Healthcare and rehabilitation | Conceptual article/ scoping review | | We define engagement as a multifaceted state of affective, cognitive, and behavioural commitment or investment in the client role over the intervention process<br>We therefore define client engagement as a multifaceted state of motivational commitment or investment in the client role over the treatment process. | About the engagement construct:<br>• engagement as both a child and family level construct<br>• older frameworks focus more on overcoming barriers for therapy and not on optimising engagement or the role of the therapist<br>• three components: affective involvement (emotional involvement in the process and with the therapist); (b) cognitive involvement (beliefs about the need for intervention and therapy effectiveness); and behavioural involvement (in-session participation; behavioural collaboration; and beliefs about personal self-efficacy to carry out agreed-upon intervention outside of treatment)<br>• engagement components reciprocally influence one another |
| Bright et al.<br>2015<br>New Zealand<br>[57] | Healthcare and rehabilitation | review | | Engagement is a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a therapeutic program, which enables the individual to become an active, committed and invested collaborator in healthcare. | About the engagement construct:<br>• engagement conceptualised in two inter-related ways, as a process (engaging with) and a state (engaged in)<br>• the state of engagement as an internal state expressed through observable behaviours<br>• important to see differences to other concepts: involvement exists on a continuum from being passive recipients of information through to autonomously making decisions |

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**Table 3.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| | | | | | on measuring engagement<br>• measures that consider engagement should include items that better represent this multidimensional concept → need to consider how to best measure the internal state of engagement |
| Harashitha<br>2015<br>India<br>[39] | Management | Review | | Employee engagement is an employee's commitment to, involvement with, emotional attachment to, and satisfaction with their work and organisation | About the engagement construct:<br>• three dimensions of employee engagement: psychological process; emotional state; behavioural state |
| Moreira et al.<br>2015<br>Portugal<br>[55] | Educational psychology | Study on student engagement of students with and without SEN | 388 students with and without SEN (mean age 13,46) | 'School engagement is a multidimensional construct<br>including contextual, behavioural, emotional, and cognitive components' | Specific measures:<br>• used instrument Student Engagement Instrument (SEI)<br><br>About the engagement construct:<br>• school engagement as a multi-dimensional construct<br>• students' engagement with school as an interactive process → result of how school meets the cognitive and psychological needs of the student |
| Rieckmann et al.<br>2015<br>International<br>[63] | Healthcare and Rehabilitation | Conceptual article | Workshops/expert panel with researchers und experts from practice (multiple sclerosis) | The US Centre for Advancing Health defines patient engagement (sometimes known as 'patient activation') as 'actions individuals must take to obtain the greatest benefit from the healthcare services available to them' | About the engagement construct:<br>• represent the primary thoughts of the MS in the 21st Century Steering Group<br>• patients are required to change their role from healthcare 'receiver' to 'engager'<br>• role of the health- care professional also needs to evolve from being a 'provider' of healthcare to become a 'motivator' and 'supporter'<br>• Patient engagement can be practiced at the macro (system), meso (institution), and micro (medical encounter) levels |
| Kumar and Pansari<br>2016<br>USA<br>[42] | Economics/Marketing | Instrument development | CE: 762 customers from different firms<br>EE: 750 employees of 30 companies | We define engagement as the attitude, behaviour, the level of connectedness (1) among customers, (2) between customers and employees, and (3) of customers and employees within a firm Employee engagement (EE) has been defined as a multi-dimensional construct which comprises of all the different facets of the attitudes and behaviours of employees towards the organisation. | Specific measures:<br>• develop survey measures for CE (Study 1) and refine existing scales for EE (Study 2)<br>• 16-item survey for measuring CE<br>• survey items used to measure EE were adapted and refined from earlier research of the authors<br><br>About the engagement construct:<br>• customer engagement (CE): engagement is represented as either a state of mind or an activity beyond purchases.<br>• study also provides a strong theoretical rationale and empirical evidence for the positive impact of high engagement scores on firm performance |

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**Table 3.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| Megha<br>2016<br>India<br>[43] | Management | Review | | Quote 15 different definitions:<br>Earliest: Kahn [40]<br>Latest: an individual employees' cognitive, emotional and behavioural state directed towards desired organisational outcomes. | About the engagement construct:<br>• term engagement has become so ambiguous that it is rare to find two researchers defining it in the same way<br>• no perfect consensus from all the official definition in the research literature for the term engagement<br>• different approaches to phenomenon: Need-satisfying Approach; Born-Out Antithesis Approach; Work-Engagement Approach; Satisfaction-Engagement Approach; Multidimensional Approach |
| Dhanesh<br>2017<br>Dubai<br>[47] | Educational Psychology | Conceptual article | | Engagement is an affective, cognitive, and behavioural state wherein publics and organisations who share mutual interests in salient topics interact along continua that range from passive to active and from control to collaboration, and is aimed at goal attainment, adjustment, and adaptation for both publics and organisations. | About the engagement construct:<br>• despite a lack of clarity on the concept, research on engagement has been booming<br>• conceptualisation of engagement as a multidimensional concept<br>• need to include affective and cognitive elements in definition |
| Graffigna, Barello and Bonanomi<br>2017<br>Italy<br>[58] | Healthcare and Rehabilitation | Conceptual article | 352 Italian-speaking adult chronic patients | In previous studies, patients' engagement refers to the ability of patients to give sense and to adjust to their disease and their actual care condition. | Specific measures:<br>• self-administered online questionnaire used: included validated measures and *ad hoc* items - Patient Health Engagement Scale (PHE-S); Patient Activation Measure (PAM-13); Morisky Medication Adherence Scale (MMAS-4); Health Care Climate Questionnaire (HCCQ); Self-Assessment Manikin Scale (SAM); demographic and clinical characteristics<br>• results confirmed relationship by demonstrating that patients' activation is associated to their reported treatment adherence<br><br>About the engagement construct:<br>• concept of patient activation often overlaps with one of patient engagement<br>• described process of healthcare journey in its four evolving phases (blackout, arousal, adhesion, eudaimonic project) → Patient Health Engagement Model (PHE-model) |
| Hollingshead et al.<br>2017<br>USA<br>[52] | Educational Psychology | Review | Students without; at risk; and with disability | 'engagement as a multilayered, complex concept that involves emotional, cognitive, and behavioural components'. | About the engagement construct:<br>• engagement as a multi-layered, dynamic concept<br>• incorporates an emotional, cognitive and behavioural components<br>• ecobehavioural approach and behavioural approach both focussed on behavioural/ |

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**Table 3.** Continued.

| Author<br>Year<br>Country<br>Reference | Field of research | Type of study | Researched population | Definition<br>(quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| | | | | | observable aspects → miss complexity/interaction with cognitive and emotional aspects<br><br>on measuring engagement:<br>• concept of engagement for students without and with disability is the same, yet often studied/defined differently |
| Ho Kim, Park and Kwon<br>2017<br>South Korea/USA<br>[41] | Management | Instrument development (validation) | Study 1: 307 workers from 12 companies<br>Study 2: 342 workers from 12 companies | Engagement is defined as "a positive, fulfilling, work-related state of mind that is characterised by vigour, dedication, and absorption" | Specific measures:<br>• Used instrument: Korean version of Utrecht Work Engagement Scale<br>• nine-item UWES-K has been determined to be an adequate measure of work engagement in Korean white-collar workers<br>• results of this study show that the concept of work engagement can be used in the South Korean context |
| King et al.<br>2017<br>Canada<br>[59] | Healthcare and Rehabilitation | Instrument development | Samples 1–3: total of 10 observers who made ratings while taking part in training sessions<br>Sample 4:<br>10 service providers in an interview study | engagement was defined as a multifaceted state of affective, cognitive and behavioural involvement in the intervention process, which motivates clients to work on intervention tasks outside of therapy | Specific measures:<br>• described the development and initial properties of a conceptually grounded measure<br>• developed instrument: Paediatric Rehabilitation Intervention Measure of Engagement-Observation (PRIME-O)<br>• measure's utility and psychometric properties emerges through examination and use over time<br>• more behavioural signs were observed/reported for children and more cognitive signs of engagement were observed/reported for youth and parents<br>• evidence of excellent interrater consensus, construct and content validity of the instrument<br><br>About the engagement construct:<br>• consider engagement to be a multifaceted optimal client state comprising a hopeful stance (affective involvement); conviction with respect to the appropriateness of intervention goals and processes (cognitive involvement); and confidence in personal ability to carry out the intervention plan (behavioural involvement)<br>• engagement in children's services is likely different from adult health care.<br>• unidimensional measures are not as useful or valid as multidimensional ones |
| Madan<br>2017<br>India<br>[38] | Management | Conceptual article | | Employee engagement: employees' willingness and ability to contribute to company success. Another way to think about engagement is the extent to which | About the engagement construct:<br>• employee engagement is so vast that it covers almost all the aspects that come under the scope of human resource management |

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**Table 3.** Continued.

| Author Year Country Reference | Field of research | Type of study | Researched population | Definition (quoted from full text) | Key content/results on engagement construct; used/developed measures |
|---|---|---|---|---|---|
| | | | | employees put discretionary effort into their work, in the form of extra time, brainpower and energy. | • multiple components to engagement: cognitive, affective, behavioural<br>• multiple stages of engagement (based on Maslow's need hierarchy): satisfied; motivated; committed; and advocate stage |
| Mayhew et al. 2019 United Kingdom [62] | Healthcare and Rehabilitation | Instrument development | | Engagement as a purposeful act, with collaboration and cooperation being an active choice on the part of the patient and done in order to maximise outcomes or improve their experience of receiving an intervention | About the engagement construct:<br>• comprised five dimensions: attendance, need for physical or verbal prompts to participate, positive attitude towards the therapy activity, acknowledgement/acceptance of need for services, active participation<br>Specific measure:<br>• Hopkins Rehabilitation Engagement Scale (HRERS-RV)<br>• Measure developed for the rehabilitation-setting<br>• Adapted for reablement context in England (reablement version – RV) |

### *Leisure research*

Studies from leisure research viewed involvement as a complex and multidimensional construct [28,30–35]. Havitz and Dimanche [30,p.346] define leisure involvement, based on Rotschild's definition from 1984, as '*an unobservable state of motivation, arousal or interest towards a recreational activity or associated product. It is evoked by a particular stimulus or situation and has drive properties*'. With minor variations in the formulation, this definition remained consistent in later publications in leisure research and sports-management, which were included in this review (see also Table 2) [28,31–35]. However, authors from leisure research [33] and sports-management [31] base their understanding of involvement on what has been established in consumer research in the 1980s [21,29].

A measure specific to the leisure context is the '*Modified Involvement Scale*' (MIS) [33]. The self-report MIS questionnaire consists of 15 items related to a specific activity, answered on a five-point Likert scale. The questionnaire is split into three items for each of the five dimensions (*attraction; centrality; social bonding; identity affirmation; identity expression*) [33].

In leisure research, involvement is seen as a multidimensional construct [28,30–35]. Havitz and Dimanche [30] incorporated the four dimensions of importance, pleasure, sign, and centrality of lifestyle into their conceptualisation of leisure involvement. Publications after the millennium primarily divided involvement into five dimensions. Within sports management, Funk and James [28] identified the dimensions of attraction, sign, centrality to lifestyle, risk probability, and risk consequence. Three recent publications [33–35], all representing leisure research, include the facets of attraction, centrality, social bonding, identity affirmation, and identity expression – the latter being similar to sign – in their understanding of involvement. Attraction refers to a combination of the individual's perceived importance, preferences, and pleasure towards a specific activity or product [30]. Centrality (to lifestyle) refers to the extent to which the individual's lifestyle choices and personal investment are structured around an activity [34]. Social bonding explains the social ties that bind the individual to a specific activity [33]. Identity affirmation includes the degree to which a leisure activity offers opportunities to affirm the self to oneself. Identity expression or sign is how one can express this self to others [33]. Finally, Surhartanto et al. [36] conclude that while the dimensions of involvement have varied between authors, the most relevant

dimensions might be importance, centrality and self-expression.

### Engagement

For the engagement construct, 27 relevant publications were found. These studies were divided into management/economics [37–43], educational psychology [44–55], and healthcare and rehabilitation [24,56–63]. A more detailed overview of the included publications on engagement can be found in Table 3.

#### Management and economics

The earliest definition included in this study was formed 1990 by Kahn [40,p.694], who referred to personal engagement (in a work context) as the '*harnessing of organisation members' selves to their work roles; in engagement, people employ and express themselves physically, cognitively, and emotionally during role performances*'. Here the three dimensions of 'physical engagement', 'cognitive engagement', and 'emotional engagement' are incorporated into a multidimensional construct of engagement.

Later, scholars in the field of human resources management further specified engagement, using the term 'employee engagement'. This did not focus on the individual, but on how employers could motivate their employees and make them work harder [37,64], or improve the employees' satisfaction with their job and/or organisation [38,39,41]. Consistent in many publications in the management sector is the approach to engagement as a multidimensional or multi-layered construct [38–41].

#### Educational psychology

Another area of research that has studied the engagement construct extensively in the field of educational psychology – mostly in a school context, calling it 'student engagement'. However, many publications/studies in this field lack a common definition [44,45,47,49,50,55]. This signifies that researchers need to clarify how they define the construct in their specific studies [44]. Axelson and Flick [46] argued that the origins of the student engagement construct are grounded in the 1980s' understanding of 'student involvement', defined by Alexander Astin as '*the quantity and quality of physical and psychological energy that students invest in the college experience*' [46,p.40].

Common to the understanding of engagement in educational psychology is the multidimensionality of the construct. Most of the authors in this scoping review included several dimensions in the definition. There is a behavioural or social dimension, as well as a cognitive and an affective, emotional or psychological dimension [44–47,49,50,52,55]. In the context of the affective dimension, authors use the terms 'affective', 'emotional', and 'psychological' interchangeably, describing the same aspects for engagement. Specific to the educational setting, several authors divided the observable behaviours related to engagement into a social/behavioural component and an academic dimension [44,45,49].

Combining all components in educational psychology, engagement is often referred to as a meta-construct [46,50]. Finn and Zimmer [49,p.102–103] define each sub-dimension: academic engagement is seen as the '*… observable behaviours related directly to the learning process …*'; behavioural/social engagement as the '*… extent to which a student follows written and unwritten classroom rules of behaviour …*'; cognitive engagement as '*… the expenditure of thoughtful energy needed to comprehend complex ideas in order to go beyond the minimal requirements …*'; and affective/emotional/psychological engagement as the '*… emotional response characterised by feelings of involvement in school as a place and a set of activities worth pursuing …*'.

Traditionally, observable components of engagement have been prioritised for the evaluation of engagement. Several authors have pointed out that a focus on the cognitive and affective components is now necessary [44,45,52]. To study the cognitive and affective components, self-reported measures such as the 'Student Engagement Instrument' (SEI) [45] and the 'Motivation and Engagement Scale' (MES) [54] have been developed and tested for their psychometric properties. The SEI measures the student's level of cognitive and affective engagement in their specific school environment [45]. The MES measures the students' motivation and engagement towards learning, how to study, and their perception of themselves as a student. There are different versions for different settings, like Primary School (MES-Junior School; MES-JS), High School (MES-HS), or Collage and University (MES-UC) [65].

#### Healthcare and rehabilitation

Discussion on the engagement construct within healthcare and rehabilitation, included in this scoping review, started in the first decade of the 2000s. For the development of the Hopkins Rehabilitation Rating Scale (HRERS), Kortte et al. [60,p.881] define rehabilitation engagement as

> … a construct that captures multiple elements, including a patient's attitude toward the therapy, his/her level of understanding or acknowledgment of a need for treatment, the need for verbal or physical prompts to participate, the level of active participation in therapy activities, and the level of attendance throughout the rehabilitation program.

Later, Lequerica and Kortte [61] specified that rehabilitation engagement is specifically focussed on the rehabilitation or therapy process, being the effort and commitment the patient shows in working towards the goals of the intervention, through both active participation and collaboration with the treatment provider. This is in accordance with the conceptualisation of engagement by 'The US Centre for Advancing Health', quoted by Rieckmann et al. [63,p.204] as '… *actions individuals must take to obtain the greatest benefit from the healthcare services available to them*'.

Algeria et al. [56] limited the construct of engagement to the attendance of scheduled health appointments, whereas King, Currie and Peterson conceptualised engagement as a multidimensional construct, defining engagement as '… *a multifaceted state of affective, cognitive, and behavioural commitment or investment in the client role over the intervention process*' [24,p.2]. King et al. [24] defined engagement as a combination of an affective, a cognitive, and an observable behavioural component. All these components influence one another. King et al. [59] used this definition when developing the 'Paediatric Rehabilitation Intervention Measure of Engagement-Observation' (PRIME-O). In the Prime-O the healthcare professionals fills out an observation-protocol on the clients engagement in relation to eigth observable indicators of engagement [59].

In their review of the engagement construct in healthcare and rehabilitation Bright et al. [57] viewed engagement as both a state of being 'engaged in' (e.g. activity) and a process of 'engaging with' (e.g. someone). They agreed on the multidimensionality of the construct and argued for measures that include items focussing on the internal state of engagement. Bright et al. [57] also pointed out the difference between engagement and involvement, with involvement existing on a continuum – from being a passive recipient of information to being autonomously in one's decisions – and, engagement being more than that, and incorporating active partaking in the specific activity.

Based on prior research by Bright et al. [57], Mayhew et al. [62] adapted the HRERS for the reablement context in England. In this context, they define engagement based as '*a purposeful act, with collaboration and cooperation being an active choice on the part of the patient and done in order to maximise outcomes or to improve their experience of receiving an intervention*' [62,p.778]. They also give five dimension for the observation of patient engagement in the reablement context. These consist of attendance, need for physical or verbal prompts to participate, positive attitude towards the therapy activity, acknowledgement/acceptance of need for services, active participation

## Discussion

The results from this scoping review indicates that the two subdimensions of participation need to be separated, with involvement being a more stable internal state of interest towards an activity and engagement refering to the specific in behaviour, emotions, and thoughts meanwhile participating in a specific setting. However, both constructs also overlap at some points and interact with each other.

### *Involvement*

The scoping review identified two fields of research that both defined and measured involvement – consumer research [21,29] and leisure research [30–36]. Since one of the main goals and outcomes of rehabilitation interventions is increasing participation [12,15], the conception given in leisure research – focussing on leisure activity and products associated with them – seems closer to rehabilitation than consumer research – focussing on the consumption of products by consumers. There seems to be a consensus on defining involvement as an unobservable state of motivation, arousal or interest towards a specific activity or product [28,30–35]. This internal state is triggered by a specific stimulus or situation. Moreover, leisure research agrees on the multidimensionality of the construct, with the earlier described five sub-dimensions, (*attraction; centrality; social bonding; identity affirmation; identity expression*) [33–35]. Surhartanto et al. [36] argue that of these dimensions, attraction, centrality and identity-expression might be the most relevant. Havitz and Mannell [66] further distinguish between 'situational involvement' and 'enduring involvement'. The former is more connected to an individual situation and context, while the latter describes a more stable state over a long time period. In regards to measuring involvement, Havitz and Mannell [66] argue that situational involvement can only be measured validly in the

individual situation since it depends to a large extent on the specific context – as engagement does. In the view of the authors, possible measure of participation will assess the general patterns of participation and levels of involvement towards different activities (enduring involvement).

An important take-home message of this study is that involvement seems to be an internal state (e.g. 'interest in' football, classical music, etc.) that can affect the individual's behaviour [21,31]. It is hardly observable because it does not imply actively executing the activity. A youngster with disability could, for example have high levels of involvement with football without ever playing the game, by being most interested in the 'product' of football (e.g. professional football leagues). Of course, this interpretation depends on how far one stretches the concept of participation. Is someone already participating in football simply by watching a match on TV, or does one have to be on the pitch, kicking the ball? Following the general definition of participation in the Oxford dictionary, the former version would not be sufficient [11].

Existing measures of involvement are often proxy and retrospectively rated, focussing on enduring involvement. Since involvement seems to be an internal state it would probably be difficult to capture involvement by someone else than the child or youth itself, or for them to recreate how they might have been thinking or feeling at an earlier time when they were 'involved'. The lack of self-report or self-ratings in healthcare and rehabilitation is therefore a limitation and needs to be addressed [8]. Furher, since involvement seems to be a rather stable internal state it could perferably be measured longitundinally.

### Engagement

A similarity finding in the literature from economics/management, educational psychology, and healthcare and rehabilitation is the multidimensionality of the construct of engagement, consisting of an observable component of '*behavioural engagement*' and two unobservable components '*affective/emotional/psychological engagement*' and '*cognitive engagement*' [24,40,44–46,49,50,54,59].

Using football as an example once again, an adolescent could engage in the activity during physical education lessons. In that situation, she could follow all the rules, having many effective contacts with the ball, and contributing to the team's success (high level of behavioural engagement), yet feel uncomfortable and experience a poor relationship with the teacher and/or team-mates (affective engagement). Moreover, one might not see any value in the activity for future endeavours or personal development (cognitive engagement), since it teaches the individual no skills that will be needed in future life. For example an adolescent might participate in football for different reasons: in order to participate together with friends, in order to compete in tournements, or just to stay fit. In this case, the individual would have a low level of cognitive and affective engagement.

A definition of engagement across all the included fields of research, should comprise the individual's behavioural, cognitive and affective investment during role performance. Role performance implies that the individual is executing and experiencing their specific role, for example, as a student, playmate, player in a sports team etc., in a specific context (e.g. school, peer group, sports club). Going back to the football example our youngster might participate in playing football at P.E. lessons as a student in order to earn grades, or playing football as a peer together with friends just for fun, or as a team-mate in a sportsclub in order to compete. Eventhough participation take place in the same activity every time, the different contexts will effect the person's role, motivation and the expectations towards the activity. This scoping review has shown that the unobservable aspects of engagement are subjective [44,45,49,57,60]. Most definitions refer to a specific role – often already applied in the terminology – in a specific context. In management and economics authors speak of '*employee engagement*' in the context of a specific work environment, organisation, or company [38,39,42,43]; in educational psychology, scholars speak of '*student engagement*' in the specific context of a school [44,46,49,50,52]; and in healthcare and rehabilitation researchers refer to '*client engagement*' [24], or '*patient engagement*' [57,63] in the context of a rehabilitation, or therapy interventions. This notion of different contexts influencing the individual is in line with the transactional framework for paediatric rehabilitation, proposed by King et al. [67], were the authors argue that transactional processes between diffenrent contexts and individuals lead to development.

A change in setting (e.g. transitioning through school) will also influence the subjective perception of the child/adolescent regarding its experience during participating in an activity. Accordingly, before measuring engagement, a definition of both role and setting is necessary in order to choose an appropriate

measuring instrument. Moreover, data on engagement of a child/adolescent in one setting may not automatically be transferred to another setting. Furthermore, engagement is always connected to the actual execution of, or participation in, a specific activity, in a specific context/setting.

Within educational psychology, healthcare and rehabilitation, researchers have pointed out that in the past the observable components have dominated the measurement of engagement, and that a focus on the internal and subjective components is now required [8,15,45]. To examine the subjective, unobservable components of cognitive and/or affective engagement self-reported instruments like the SEI [45] or the MES [54] in educational psychology are necessary. In healthcare and rehabilitation, engagement has thus far mainly been assessed by referring to medical records and frequency of attendance [56], therapist-reported questionnaires like the HRERS [60] or HRERS-RV [62], or observable protocols like the PRIME-O [59]. At the same time, Adair et al. have recommended more self-reported instruments [8].

### Relationship between involvement and engagement

In educational psychology, Axelson and Flick [46] argued that even though student engagement is grounded in student involvement theory from the 1980s, the two concepts may have grown apart over time. Duchan [48] specified the difference between the constructs, saying that engagement is a display of 'involvement in action'. This can be supported within healthcare and rehabilitation by Bright et al. [57], who argue that being active in the specific setting of therapy is the necessary component that separates engagement from involvement, making involvement a precondition for engagement.

The fact that authors in healthcare and rehabilitation [59] or educational psychology [49] label their sub-dimensions of engagement with behavioural, affective or cognitive '*involvement*', or use the term '*involvement*' in their descriptions of the engagement construct, makes the discussion difficult. At the same time, such cases exemplify the ongoing confusion about the two constructs.

From the perspective of this scoping review – searching for definitions on involvement and engagement, especially feasible for measure development – the constructs of involvement and engagement need to be separated. Involvement describes a general internal interest and arousal towards, or motivation for, a specific activity or activity-related product, whereas engagement refers to the specific demonstrated behaviour and internal experience while performing an activity in a specific setting. Undoubtedly, both concepts interact with one another and are likely to be transactional. High levels of involvement (i.e. interest in professional football) may support a willingness to engage in the activity and interact with others in a given activity/situation (i.e. attending training at a football team/club); and positive experiences while engaging in an activity may positively affect the person's subsequent level of involvement. Thus, both constructs overlap, especially when comparing situational involvement and the internal aspects of engagement. When measuring participation in general, researchers should focus on enduring involvement for the general interest in specific activities (e.g. football). Cognitive and affective engagement are to be measured context-specific (e.g. the experience of participating in football during P.E. lessons at school).

Following the understanding of the involvement and engagement constructs in this scoping review, one could consider rephrasing the definition of participation in the ICF ('*involvement in life situation*' [12,p.9]) into 'engagement in life situations'. Involvement in a life situation would merely describe a person's interest, or perceived relevance towards, a specific life situation or setting, be it education, work, or leisure. This does not necessarily imply taking part in the life situation. Moreover, the footnote in the ICF, describing the WHO's understanding of involvement – '*… 'involvement' incorporate taking part, being included or engaged in an area of life, being accepted, or having access to needed resources*' [12,p.13] – seems much more congruent with the concept of engagement in the literature reviewed in this scoping review. '*Taking part*' would reflect the behavioural dimension of engagement and '*being included*' or '*being accepted*' would reflect the affective dimension of engagement. This approach is similar to Krieger et al. [68, p.2], who extent the ICF definition in the context of adolescents with autism spectrum disorder as '*… being engaged in and/or performing meaningful activities in occupational and social roles …*' Approaches like that could enrich the ICF-framework and might give it more clearity.

With regard to the fPRC model [7], the findings of this scoping review point towards an argument that characterises involvement in a way that most sources

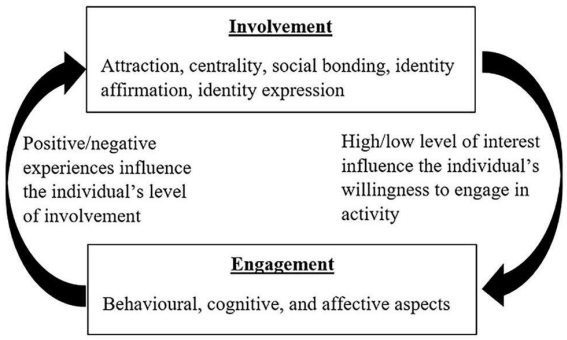


**Figure 2.** Relation between involvement and engagement.

of this review would define as engagement. This accounts mostly for the statement '… *experience of participation while attending* …' [7, p.18] in the fPRC-model's definition of involvement, which literature in this review would use to describe as engagement. At the same time, Imms et al. [7] refer to personal preferences, as a separate intrinsic factor of participation. Where the fPRC-model sees engagement more as a precondition of involvement, which the literature of this review connects to the involvement sub-dimension of attraction. The results of this scoping review lead to the argument that it might be the other way around, with involvement as an internal state of motivation, working as a prerequisite of engagement. However, this might be a 'what was first: egg or hen?'-argument, since both constructs may interact in a kind of loop effect (as shown in Figure 2). Therefore, it strongly dependends on the individual's standpoint.

This study has to recognise some limitations. The main one would be that most of the screening and charting was executed by one person (the first author). Moreover, the number of fields of research and databases searched this was not deemed feasible. Future studies, focussing on singular aspects in single fields of research, should use fewer index words and limitations, to wider the scope of publications included in the first round of screening. This could, for example, also increase the variety of perspectives within one field of research. The choice of databases can also be discussed as other databases may have given other perspectives. No evaluation was done of the studies quality regarding their risk of bias. Since the aim was to evaluate the definition of constructs and not the effect of interventions the evaluation was conisered to not be necessary.

## Conclusion and future directions

This scoping review explored knowledge from other and partly unreleated fields. The results gained, point in a direction that the two subdimensions of participation need to be separated, with involvement being a more stable internal state of interest towards an activity and engagement refering to the specific in behaviour, emotions, and thoughts meanwhile participating in a specific setting. However, both constructs also overlap at some points and interact with each other. This knowledge is useful in the development of self-reported measures of participation for occupational theapists in the field of paediatric rehabilitation as well as in other fields or for other professionals. The subdimension, involvement, can be used for measuring general participation of the individual longitudinally, since it is assumed to be rather stable over time. However, engagement, being connected to a specific settings, could be used when evaluating participation in specific activities in specific settings. The results of this study may be useful for future research in this area.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

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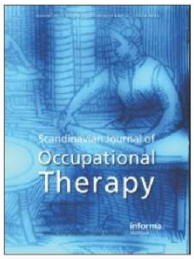
Article 2



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# Perceived facilitators and barriers for participation in leisure activities in children with disabilities: perspectives of children, parents and professionals

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# Perceived facilitators and barriers for participation in leisure activities in children with disabilities: perspectives of children, parents and professionals

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**ABSTRACT**

**Background:** There is limited knowledge about facilitators and barriers to leisure activity participation for children with disabilities in Norway, which is needed to improve rehabilitation interventions.

**Aim:** This study aims to explore the main facilitators and barriers for participation in leisure activities for children and youth with disabilities in Norway.

**Methods:** Semi-structured group interviews with 31 parents, 20 healthcare professionals, and nine children with disabilities were conducted. Qualitative content analysis with thematic coding was used, and the model of factors affecting the participation of children with disabilities developed by King et al. was applied for further deductive analysis.

**Results:** Child factors, as viewed by parents and professionals, worked primarily as barriers and tended to increase with the child's age. The children themselves focussed on their own preferences, friendship and enjoyment as their main facilitators for participation. Most environmental and family factors worked both as facilitators and as barriers, with parental support as the most important facilitator. Differences between urban and rural areas in the availability and accessibility of activities were reported.

**Conclusion and significance:** Knowledge from this study is important for the improvement of rehabilitation interventions that aim to increase participation in leisure activities for children and youth with disabilities.

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Children; disability; leisure activities; measurement; participation; rehabilitation

## Introduction

Participation in leisure activities is important for the development of physical, social and mental health for all children and youth. It is a main goal and outcome for rehabilitation service providers [1–6]. Research has shown that children and youth with disabilities show different patterns of participation regarding recreational and leisure activities than their non-disabled peers [1,2,4,7–11]. The main differences are less participation in organized or physical activities, and more home-based, self-organized activities, or activities that include family members [4,10–13]. Patterns of participation also differ, depending on the country or region the child lives in, as shown by Ullenhag et al. [14] in an international comparison between children with and without disabilities living in different European countries. Specifically, Norway shows quite unique patterns of participation in international comparison [15]. Green et al. [15] report both higher participation rates in cultural events and physical activity for Norwegian children and youth compared to other European countries. Since family and parents are much involved also in organized activities in Norway (volunteering as coaches or team managers), they contribute to these higher participation rates also due to sociodemographic factors like higher average income and less working hours, compared to other European countries. Therefore, it is of interest how children and youth with disabilities in Norway experience their participation.

Participation is a complex and still much discussed construct [4,16–20]. One of the widely used models is

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the biopsychosocial model incorporated in the 'International Classification of Function, Disability and Health' by the World Health Organisation [21]. There, participation is defined as 'involvement in life situations' [21, p.10]. However, despite its wide use the conceptualization of participation given in the ICF has received criticism from different researchers [11,17,18,20]. Main critique was a lack of theoretical clarity, or the individual's subjective perspective on participation. In a recent comment, Mitra and Shakespeare [20] argue for a remodelling of the ICF to reflect the progress regarding the knowledge about the participation construct. This is in line with the argument of Adair et al. [22], who in their recent systematic review on participation measures conclude that the construct of participation is under constant development. This puts pressure on theory and measure development to adjust to this developmental process. In the view of the authors, participation is a multidimensional construct including both an objective and a subjective perspective. Therefore, when researching participation a focus on the individual's perspective is of high significance.

Better understanding of the patterns of participation in leisure activities, including facilitating and hindering factors, is required [23]. Individual and environmental factors can be both barriers and facilitators, depending on the situation and the context [17,24–26]. However – to the knowledge of the authors – there is a lack of knowledge on barriers and facilitators for participation in leisure activities in children and youth with disabilities in Norway thus far. The ICF includes personal and environmental factors as either barriers or facilitators. This has been critiqued by Hemmingson and Jonsson [17]. Therefore, when researching facilitators and barriers a model, where factors can be seen as both facilitators and barriers is needed. King et al. [1] have presented a differentiated model of factors affecting the participation of children with disabilities, which identifies 11 factors divided into three main categories: child, family and environmental factors. The child factors include the 'child's perception of its own athletic and scholastic competence', 'the child's physical, cognitive and communicative function', 'the child's emotional, behavioural and social function' and 'the child's preferences'. Family factors are the 'financial and time impact of the child's disability on the family', 'the family's demographics', 'a supportive home environment' and 'the family's preferences for recreation'. The third category of environmental factors includes 'a supportive physical and institutional environment', 'supportive relationships for the child', and 'positive relationships for the parents'. In the view of the authors, this model gives a more detailed perspective on facilitators and barriers for participation in leisure activities – especially with a higher focus on the individual's perspective – than the ICF. The model of King et al. is chosen as a theoretical framework for the present study. A more detailed definition of the model's included factors is presented in the results.

So far, research on facilitators and barriers for participation has often focussed on the perspective of parents. However, different studies have found success in including other perspectives, such as professionals working closely with children and youth with disabilities [7,26–28]. Wright et al. [27] call healthcare professionals the perhaps missing link to improve an active lifestyle and encourage behavioural change in individuals. Moreover, in recent years it has become more and more important to include the perspective of the children themselves [29–35]. This is especially stated in article 12 of the UN Convention of the Rights of the Child (UNCRC):

> *'[…] assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child […]'* [29, p.4]

Therefore, it is of interest to explore the different perspectives of parents, professionals, and children and youth with disabilities regarding facilitators and barriers for participation.

The research question for this specific study was: What are main facilitators and barriers for participation in different leisure activities for children and youth with disabilities in Norway, based on the perspectives of parents, professionals and children and youth with disabilities?

## Method

A qualitative design was used to explore and describe facilitators and barriers for participation in children with disabilities. Group interviews were conducted to explore the perspectives of parents, professionals, and children and youth. The study was approved by the Norwegian Centre for Research Data to meet all ethical research criteria (reference number 52305/3/STM).

### *Recruitment and participants*

Participants were recruited at a rehabilitation centre in Norway during a three-week intensive group

intervention based on adapted physical activity. Inclusion criteria for parents were having a child with disability aged between 5 and 17 years, and speaking Norwegian. Inclusion criteria for the children were being diagnosed with some kind of disability, being able to partake in the interview on their own, and being able to give informed consent (with support from parents). In order to handle the challenges of appropriately interviewing children with disabilities as a vulnerable population, the guidelines introduced by Lewis and Porter were applied [36]. These guidelines provide researchers with a checklist to adapt the research methods required when interviewing children with special needs for their specific research aim. The checklist includes how to get access to young interviewees, discuss questions of consent and assent, confidentiality and anonymity, recognition and feedback for the interviewees, and the researchers' social responsibility. It also provides guidance for sampling, design and proper communication.

Potential children and parents were invited to a short information meeting regarding the aim of the study. Consent forms and additional sociodemographic questionnaires were distributed. To further build trust and a positive relationship with the children, the first author participated in two days of intervention programme with each group.

The professionals were employees at the rehabilitation centre (e.g. physician, physiotherapist, occupational therapist, teachers), working with approximately 500 children and youth with disabilities per year. They were recruited in short information meetings where consent forms and a short sociodemographic questionnaire were distributed. Inclusion criteria were at least one year of working experience at the rehabilitation centre, and speaking Norwegian.

All together 61 people participated in interviews (32 parents, 20 professionals and nine children). The group of parents included seven fathers and 25 mothers. According to the sociodemographic questionnaires, 17 participants characterized their child's disability as physical, six as intellectual or emotional, and eight as complex.

Regarding the group of parents, in most cases (26), the child lived together with both parents. Most parents were of Norwegian heritage. Other heritages included the Middle East (4), other European countries (3), East Asia (2) and Africa (1).

Most parents worked full-time. Four parents, all mothers, were not employed in order to take care of the child with a disability.

The group of children, having a variety of impairments, was five boys and four girls. Their ages ranged from seven to 15 years (mean 11.1 years). Often the parents of the interviewed children also participated in a separate interview for parents. However, this was not the case for all children. Furthermore, to assure anonymity – such connections between the children and parents interviewed were not recorded. Group size in the children interviews varied between two and four, with one individual interview, two interviews with two and one interview with four children.

The group of professionals was eight men and 12 women. Their average job experience was seven years. They comprised four physicians, four sports pedagogues (with a bachelor or master degree in sport-science and a focus on pedagogics and adapted physical activity), four leisure activity leaders, three physiotherapists, two teachers, two team assistants and one occupational therapist.

Once informed consent was received from parents, children and professionals, the group interviews were planned and conducted.

### Data collection

The group interviews took place in a meeting room at the rehabilitation centre. Data collection took place during spring and summer 2017. The group size was set to a maximum of eight participants [37]. Other studies have successfully used similar methods in researching participation for children and youth with disabilities [2,7,9]. The interview guide used was inspired by that of Coster et al. [2] during the development of the 'Participation and Environment Measure for Children and Youth' (PEM-CY) and has been adapted to the different research groups (Table 1).

The first author conducted all 16 interviews: seven with groups of parents, five with groups of professionals and four with groups of children and youth. The interviews varied from 35 and 50 min, and were digitally recorded (both audio and video). For the interviews with children, parents were offered the opportunity to observe the interviews, or assist their children if needed. However, none of the parents did so.

Saturation for the interviews with parents and professionals occurred after six interviews (parents), respectively, five interviews (professionals), when no new aspects occurred in the interviews. To assure this assumption, one more interview for each group was conducted. In the case of the children, even though only nine children participated in the interviews no new themes occurred after the four conducted interviews.

**Table 1.** Interview-guide (translated from Norwegian to English).

| | Parents | Professionals | Children/youth |
|---|---|---|---|
| 1 | What does 'participation' mean to you? (no correct or wrong answers) | | – |
| 2 | What kind of leisure activities does your child participate in at home, with friends, or in other organized or unorganized settings? | What kind of leisure activities do you think children with or without disabilities participate in at home, with friends, or in other organized or unorganized settings? | What kind of activities do you do at home, with friends or somewhere else during your leisure time? |
| a | – | – | Are there any activities you do, that you actually don't want to do? |
| b | – | – | Are there any activities you would like to do, but you can't do thus far? Why is that? |
| 3 | How do you evaluate your child's participation? | How do you evaluate a child's participation? | – |
| a | What are your key aspects to evaluate participation? | | – |
| b | If you take an activity we mentioned before, what will give you the sense that your child is participating? | | – |
| 4 | What facilitates your child's participation in leisure activities? | Which factors do you think can help children and youth with disabilities to participate in leisure activities? | What helps you to make it easy and fun to participate? |
| a | Which factors are helping (e.g. persons, physical environment, equipment, strategies, time …)? | | Are there any persons, equipment or other things that help you? |
| b | In what kind of situations do these factors help your child participating? | | Is it the same in all activities you do, or do things vary between activities? |
| 5 | Which factors hinder your child from participating in leisure activities? | Which factors do you think hinder children and youth with disabilities from participating in leisure activities? | What makes it difficult or boring to participate? |
| a | What kind of challenges or barriers are there (e.g. persons, physical environment, equipment, time …)? | | Are there any persons, or other circumstances that make it difficult or boring for you to participate? |
| b | In what kind of situations do these factors hinder your child in their participation? | | Is it the same in all activities you do, or would like to do, or do things vary between activities? |
| 6 | If you could design a questionnaire for children about participation in leisure activities, what would it look like (e.g. use of pictures, pictograms, symbols, language …)? | | If you could decide what the new questionnaire should be and look like, what would be important for you? |
| 7 | Is there something else we haven't discussed today that you want to talk about? | | Is there anything else you think we should talk about today? |

Due to recruitment difficulties, an additional interview to confirm this presumption was not conducted.

Transcription took place the week following the interviews. Qualitative data were transcribed verbatim into Microsoft Word by the first author. Transcriptions were imported into MAXQDA 12 for further analysis. The participants' names were exchanged with participant-numbers. If participants mentioned their child's name, these were replaced with *'my son'*, *'my daughter'*, or *'my child'*.

### Analysis

Descriptive analyses were performed to describe the sociodemographic data and the setting for the leisure activities of the children. Sociodemographic data, anonymized by a codename, were analyzed using SPSS 24 (SPSS Inc., Chicago, IL).

The qualitative analysis followed established recommendations for qualitative content analysis [38]. All quotations from the interviews were translated from Norwegian to English, with the intent to stay as close as possible to the original quotes in use of language, formal and informal expressions, and so on. In the article, names of the participants (children, parents, or professionals) have been changed into pseudonyms. The transcripts were read through, parallel with the video and audio files, adding comments on non-verbal communication (gestures, facial expressions, expressions of emotions). The reduction phase began with a basic content analysis of the transcripts based on the interview guide. Text passages were marked according to the question in the interview guide. The model of factors affecting the participation of children with disabilities, developed by King et al. [1], was used for further deductive analysis of the interview data. Table 2 gives an example of the analysis process.

After several rounds of coding, the results were summarized in a table by category and group of participants to enhance the interpretation and reporting process. Mainly the first author, with several consultations with the last author (ASD) until consensus was reached, conducted analyses.

## Results

First, the different activities from the interviews were: (1) physical activities such as individual activities as horseback riding and swimming), team sports as for example football and handball, and family activities as go for a walk/hiking, cross-country skiing and downhill skiing. (2) Cultural activities like playing an

Table 2. Examples of the analysis process.

| Original quote | Extraction | Factor according to the framework from King et al. [1] | Conceptual theme |
|---|---|---|---|
| 'We are lucky, having a very capable occupational therapist, who has experience with problems regarding inclusion. Based on that he could make specific suggestions that worked for us. In this way we did not need to experiment too much'. | Experienced and motivated occupational therapist; suggestions from professionals help to find good opportunities for participation | Environmental factors – relationships for the parents – formal support | Facilitating participation due to support from motivated and experienced professionals |
| 'For example, when we are at the sports-club. It's not just for him (*refers to his son*), but I also get to talk with other parents. [...] These activities also work as a think-tank and in order to exchange ideas for us parents. We can't think about everything on our own. We have to exchange experiences. This is really important'. | Activities not just for own child; importance of exchange of experiences with other parents with similar challenges | Environmental factors – relationships for the parents – informal support | Facilitating participation by exchange of experiences with other parents |

instrument, singing in a choir and dancing. (3) Hobby and outdoor recreation activities as playing outdoors, fishing, being a member of a scout-group and hunting. (4) Recreational activity like use of PCs, tablets or smartphones; gaming; watching TV and just 'relaxing or taking a break'.

A major focus in leisure activities was within computer and media (e.g.). The use of PCs, tablets and smartphones included social media and use of streaming providers.

In the following the findings on barriers and facilitators are described in categories related to the frame of King et al. [1]. Table 3 gives an overview of all categories.

## Child factors

### Child's perception of his or her own athletic and scholastic competence

King et al. [1] refer to the children's perception of their own athletic and scholastic competence.

In this study, all participants (children, parents and professionals) provided information from their perspective.

*Barriers:* The main barrier for all parents and professionals was the child's own perception of his or her ability gap in comparison to peers without disabilities. As the gap increased with increasing age, low motivation, low self-esteem or even dropout from the leisure activity were experienced. One mother exemplified this:

> *'My child participated in gymnastics for one year. And then it became like, things got too fast, so she couldn't keep up. And so... well... she became almost ashamed that she didn't manage to do as much as the others. Even though the trainer was really good at adapting the activity, so she could participate, she withdrew [...]'* Sara

The children themselves did not necessarily perceive their own impairment as a barrier. Often they saw other children's impairments as more disabling, compared to their own.

*Facilitators:* Some parents explained that their children tried to find activities in which their impairment was invisible. Another strategy was to find a niche or role within the activity according to their capabilities. One father exemplified this with his son's participation in handball:

> *'My son – he is quite weak – withdraws if things get too physical, or if the other guys in a way start shoving, bopping and tossing. Especially when he should start with handball, where things can get a bit rough, he wanted to participate as a referee, see? Because in this way he could stand on his own, did not have to fight for the ball – he just stands there with his whistle. So, this was his reasoning for being the referee...'* Teodor

### Child's physical, cognitive, and communicative function

King et al. [1] define this factor as how the child functions on a physical, communicative and cognitive level, perceived by external (professional) observers.

*Barriers:* As the child got older, the parents and professionals perceived an increased gap between the child's physical, cognitive and communication functions and their non-disabled peers. This included physical functions, complex sets of rules, or complexity in strategies and tactics.

Another aspect mentioned was the child's overall level of energy. Many children use most of their energy to keep up at school, as parents and professionals explained.

Consequently, some children had an increased need for rest and sleep, affecting their opportunities for participation in leisure activities. Especially parents pointed out that clear priorities are necessary, as one mother explained:

Table 3. Overview on facilitators and barriers found in this study (categorized according to King et al. [1]).

| Factors (King et al. [1]) | Barriers | Facilitators |
|---|---|---|
| **Child factors** | | |
| Child's perception of own athletic and scholastic competence | • Demotivation/lower self-esteem due to perceived ability gap to non-disabled peers | • Finding activities where disability is not visible<br>• Finding 'niches' within activity to compensate for/hide ability gap |
| Child's physical, cognitive, and communicative function | • (Increasing) gap to non-disabled same-age peers (with age)<br>• Overall level of energy and increased need for rest/sleep | • Adaption of activity/rules according to the child's needs |
| Child's emotional, behavioural and social function | • Attention deficits<br>• General resistance/negative attitude towards (new) activities<br>• Unpredictable situations that lead to resistance against further participation | • Increased focus in individual activities or one-on-one support |
| Child's preferences | • Parents/assistants not capable/able to support the child due to own lack of ability/skills<br>• Child's abilities make participation (in the view of the parents or other adults) not possible | • Considering the child's preferences in activity choices |
| **Family factors** | | |
| Financial and time impact on the family | • Long distances<br>• Child's need for support while participating<br>• Expensive one-on-one support/lessons | • Gaming to support social participation (e.g. online gaming) or physical training (e.g. training using Wii-Sports, EA Sports Active, Xbox Your Shape, or Happy Rehab™) |
| Family demographics | • Working hours of parents<br>• Family income in conflict with high costs | • Support from Norwegian welfare system |
| Supportive home environment | • Problem in Coordination of activities (especially with several siblings)<br>• Social isolation<br>• Exhaustion due to everyday life/work<br>• Protecting child from negative experiences/emotions<br>• Physical/mental restrictions due to disability/illness of a parent<br>• Patronizing attitude of parents during participation | • Supporting autonomy of the child during participation |
| Family preferences for recreation | • Inactive home environment | • Parents or siblings as active role models |
| **Environmental factors** | | |
| Supportive physical and institutional environment | • Physical barriers<br>• Little variety of activities (especially rural areas)<br>• Little range of activities adapted for disabled children<br>• Restrictive (local) legislations/regulations<br>• General organization/structure of sport clubs in Norway/ missing resources<br>• Focus on competition especially in sports<br>• General lack of thoughtfulness in society<br>• Perceived barriers by others, which are not really barriers or can easily be overcome | • Adapting public areas to the needs of disabled people<br>• Living in urban areas<br>• General legislation connected to the Norwegian welfare state |
| Supportive relationships for the child | • Inactive/unavailable parents<br>• Child's wish for autonomy with increased age that stands in conflict with the child's realistic perspectives to be independent<br>• Activity leaders with a negative attitude/lack of knowledge towards inclusion<br>• Peers with a negative attitude towards the disabled child | • Active/supporting parents<br>• Leisure assistance<br>• Inclusive/competent activity leaders<br>• Peers with an inclusive attitude<br>• Peer group both within the disabled and the 'non-disabled' community |
| Positive relationships for the parents | • Lack of informal support<br>• Unmotivated/stressed local professionals<br>• Lack of clear responsibility | • Support from relatives/friends<br>• Exchange with other parents<br>• Motivated/experienced local professionals<br>• Advocacy groups<br>• Local welfare offices |

*'My child enjoys pretty much everything she participates in. Her problem lies in the aftermath. If she cannot go to school for two days afterwards, it may not have been the right activity… Then we have to find something that enables us to keep balance in everyday life. This is a challenge we've met…'* Ella

*Facilitators:* Parents and professionals pointed out that often already small adaptations of the setting, equipment or activity rules could enable a child's participation.

### *Child's emotional, behavioural, and social function*

This factor refers to how the child is functioning emotionally, behaviourally and socially in leisure activities [1].

*Barriers:* Parents mentioned an attention deficit due to too much stimulus, especially in group activities. This could cause missing different instructions, or spending less time on tasks compared to the peers without a disability.

Some parents also mentioned their children had a general resistance towards new activities, until they get started, as one father explained:

> *'There are for sure several children like that: everything is "no" – right until you get started and try a bit; then it may be a bit "yes" – with the exception of some things that are 'yes' all the time.'* Ulrik

Additionally, unforeseeable triggers appearing while participating can lead to the child refusing all further participation or cooperation. Often even professionals or parents had no explanation for these incidents, making it even harder for them to deal with these situations.

*Facilitators*: Parents especially mentioned that their children often coped better with individual activities (e.g. climbing, swimming), where they solely could focus on themselves and/or had one-to-one support.

### Child's preferences

King et al. [1] refer to the child's own priorities and affinities regarding leisure activities. These preferences can include both organized and unorganized activities.

*Barriers:* Parents experienced that their own lack of knowledge or ability to follow up an activity could hinder the child's participation. Another perceived barrier appeared in situations when children had unrealistic thoughts about their own capabilities, as one mother explained: her son was using a wheelchair and wanted to play football (as a field player on the pitch, scoring goals):

> *'I have a boy that grew up with a father playing football on a high level and he has been to football matches since he was born, in a way… So football has high priority. So, when spring is coming, he will likely want to participate in "football school". Even though the other parents say they want to adapt so he can participate, that might be difficult… Maybe, we have to take this fight, that this is something he cannot do… just because he does not have the abilities.'* Hedda

The children themselves mentioned disliking activities and not having chosen activities themselves as barriers. Examples included household chores that they were ordered to do, cleaning a pet's cage, helping with the dishes or walking the dog in bad weather.

*Facilitators:* Considering the child's preferences in the choice of activities was seen as a main facilitator by parents and professionals. Parents explained how this prevented discussions and conflicts, since children looked forward to participating. Professionals mentioned that prioritizing a few activities the child is motivated for would lead to better outcomes.

The children themselves focussed mainly on their preferences and activities they were interested in, as the comment of one boy exemplifies:

> *'If you choose an activity, you choose one that you really want to do. So it's always fun.'* Sebastian, 15 years

When participating with their friends, their preferences were often formed by the group's current interest.

## Family factors

### Financial and time impact on the family

According to King et al. [1], this factor refers to how the child's disability effects the family on a day to day basis. This can include time aspects (e.g. extra time for daily care, support in activities of daily living), or additional expenses connected to the child's disability (e.g. accessible home environment, adapted transportation).

*Barriers:* Parents and professionals lay most attention on the time aspect. This included time to travel long distances to activities suitable to the child's needs, or increased time need to support the child during participation, especially compared to non-disabled siblings (parent perspective) or non-disabled peers (professional perspective).

For the financial aspect, parents referred to additional expenses due to the child's need for one-to-one support during participation, as one mother exemplified with the activity of horseback riding:

> *'It becomes expensive, if you have one-to-one support during lunge lessons [in horseback riding]: You have one standing in the middle and one assistant takes care that he [her child] does not fall asleep, or falls down, and that he does what he is supposed to do. Then it becomes expensive, if it's organized activity, and you have to pay for it, since there are two adults.'* Selma

*Facilitators:* Investing in gaming equipment (e.g. PC, gaming-consoles, motion-control applications) was seen as a very effective strategy to facilitate social participation with non-disabled peers (e.g. multiplayer games both online and stationary), and/or joyful training (e.g. training using Wii-Sports, EA Sports Active, Xbox Your Shape, or Happy Rehab$^{TM}$), in the perspective of the parents and professionals. This is reflected in the argument of one father:

> *'My son is playing online with a headset and microphone, talking with the others. They are playing Warcraft and other such things. There he is as social*

*as everyone else is. Even if there are 10,000 that are sitting in each their own room, there is a common activity going on in this digital space, you understand. Then it does not matter if you are sitting in a wheelchair, where you are, or whether you maybe don't have the best pronunciation. Yes, this is a really good arena.'* Theodor

### Family demographics

This factor incorporates the parents' education, employment, and family income [1], and how these affect the child's participation in leisure activities.

*Barriers:* The level of employment was a main topic within this category in the interviews with parents and professionals. This included activities already starting within working hours of the parents, or changing working hours when parents were working shifts.

Professionals talked more about how a low family income could hinder participation, especially in case of activities that required cost-intensive equipment (e.g. downhill skiing) or was bound to high fees for participation (e.g. paying for lessons, payment for entrance in swimming pool, skiing resort).

*Facilitators:* Main facilitators were connected to financial support from the Norwegian welfare state, such as caregiver benefit for care that helped parents working less hours to support the disabled child.

### Supportive home environment

This factor refers to the physical, mental and social well-being of the parents and how well the family interacts and corporates with each other [1].

*Barriers:* Siblings with different interests were perceived as a barrier by both parents and professionals, since coordinating all these interests was challenging. Parents also talked about how the child's disability affected the social functioning of the family, isolating or excluding not only the child, but sometimes also the whole family from participation and social life.

Another aspect mentioned by parents was that they often felt exhausted after working days or weeks, without energy left to motivate their child to engage in specific leisure activities, or participate together with them.

Parents also reported protecting their child from negative experiences and emotions, which affected their own emotional well-being, as shown in a communication between two mothers:

Aurora: *'It is well known – to say it like that – that children with special needs are often standing on the side-line. They do not have the same group of friends – we parents have to compensate for a lot of that.'*

Tea: *'Like my seven-year old – he said "Why is it always me calling the others? Why is there nobody calling me?" [Other participants nod their heads and agree] This is hard.'*

Aurora: *'It is hard to be a parent in such situations. I said to the other parents [in her home community] "How shall I respond to this?" This is very sad. My daughter wants so desperately to be a part… '*

In one case, a parent had a disability and perceived that his own restrictions affected the child's participation negatively.

### Family preferences for recreation

This factor incorporates preferences for engaging in specific activities by the parents and the rest of the family [1].

*Barriers:* According to the professionals, mainly inactive parents or a family with an inactive lifestyle would hinder the child's participation in leisure activities.

*Facilitators:* Both parents and professionals agreed on how the preferences of the parents and siblings could work as a facilitator for the child's participation, working as positive role models, by participating in a variety of leisure activities themselves. As one father explained:

*"Well, another aspect is that it helps to be active oneself. We really enjoy cross-country skiing and this has also passed over to my son. Going cross-country skiing or hiking, and that we are doing this regularly, made it become a part of his activities."* Tobias

## Environmental factors

### Supportive physical and institutional environment

King et al. [1] define this factor as the physical environment, policies, and public institutions facilitate or hinder participation in leisure activities.

*Barriers:* Some participants mentioned that some community facilities still display physical barriers for children with disabilities (e.g. missing elevators or wheelchair ramps). Living in rural areas was also often perceived as a barrier, with longer distances to suitable activities or institutions, and generally little variety of available activities.

Some parents were critical that their specific communities had different minimum ages to apply as a leisure assistant. They wished for a young energetic person their child could relate to. Unfortunately, most communities had set a minimum age of 18 years or provided primarily elderly people.

A major topic for both parents and professionals was how most leisure activities were organized, especially physical activities. In Norway, most sport clubs are run on a voluntary basis, often by parents during their own leisure time. According to the participants, this led to a lack of knowledge on how to include children with disabilities, or a lack of additional resources to facilitate their participation, delegating most of this work to the parents of the disabled child. Further, most organized physical activities aim towards competition, leaving no room for including children with disabilities.

Many parents said that they missed sensitivity in how to interact with children with disabilities, or perceived that others saw non-existing barriers and a lack of trying, because of such self-constructed barriers. One mother explained this in regard to the attitude of other parents towards dealing with her son, who uses a wheelchair:

> *'I think many parents build up their own barriers. They see a set of stairs as a problem – this is no problem. I can lift him [talks about her son], I can carry him, I can help them, if they would just give it a shot.'* Aurora

*Facilitators:* Professionals argued that a lot has been done to include disabled people in society, as one professional explained:

> *'I think, as I reflect on the last decade, there has been a significant increase in customizing and adapting the physical environment. Everywhere – adapting school buildings and others. There has been a lot of construction work everywhere the last years; the last decade, actually.'* Mikkel

Living in urban areas was perceived as a facilitator, with lower distances to activities and particularly adapted activities close by, for example organized by advocacy groups. Children articulated that they thought they had a lot of opportunities in their local communities, no matter if they came from urban or rural areas.

Parents and professionals mentioned different supports connected to the Norwegian welfare state. These included cash benefit for care, or different possibilities for assistance such as respite care or leisure assistance.

### Supportive relationships for the child

According to King et al. [1] this factor describes how relations between the child and different persons (e.g. parents, peers, teachers, trainer, assistants) facilitate or hinder participation in leisure activities. Parents and professionals argued for the parents being the most relevant relationship for the child in order to facilitate participation in leisure activities.

*Barriers:* Parents with less engagement were perceived as a major barrier, according to the professionals. Conversely, too much engagement was perceived as a hindering factor with increasing age of the child, since older children want to be more autonomous in their participation. Another aspect mentioned by professionals was a regulating or dictating attitude from parents during participation.

Activity leaders, who have a negative attitude towards inclusion, or lack knowledge, also hinder the child's participation. This may lead to dropout or loss of interest in the activity. Parents and professionals also talked about how peers with excluding attitudes work as barriers.

*Facilitators:* Parents supporting their children to participate in leisure activities, mentally, emotionally and physically, had a large facilitating effect. A teacher explained the general role of parents in participation, reflecting also on being a mother herself:

> *'Well, this is really crucial, that we as parents take part: driving, picking them up, stay on the side and cheer them on, let children do the things they are excited to do. It really depends on the parents partaking, or that parents organize that the child can participate together with others.'* Julie

Supporting the child's autonomy while participating and a cautious attitude when supporting the child were perceived as facilitators, especially by professionals. With increasing age, leisure assistance was perceived as a facilitator, supporting the child's increasing wish for autonomy and independence from their parents.

Parents perceived that a third party often had better chances to motivate the child. These could be personal or leisure assistants, instructors at organized activities or other older teenagers or adults.

Activity leaders with high knowledge and a positive attitude towards inclusion were perceived as facilitating the child's participation. One mother exemplified this with her daughter's participation in a theatre club:

> *'We attend a theatre club and my daughter really enjoys herself there... For us it is working perfect. And this is because of the women leading the club: she writes some roles including a chair, so my daughter can sit a bit. She writes those roles especially for my daughter.'* Ella

Positive peer relationships facilitate participation, as one father explained using the adapted athletics group his son and other children who know each other quite well took part in:

> *'What I experienced is parents coming saying they would never have thought that their children would run a single metre, you know. But then, all of a*

*sudden, they ran a whole lap on the athletics track as a warm-up. Just because they meet others, they are friends with and start running because "That's what we are here for…" So it is this social arena, you can use for so many activities.'* Tobias

This is in accordance with the children's perspective. For them positive peer relationships were among the most important factors for participation, as two girls from different interviews stated clearly:

*'It's about being with my friends when you do things that I really like doing.'* Elinor, 12 years

*'Everybody is nice to each other, that's what makes it fun to play handball. And at the team I play in, it's a lot of fun.'* Signe, 11 years

Parents and professionals argued for the importance of interacting with both disabled and non-disabled children, to reflect the diversity of the 'real world' and prepare them for their future lives.

### *Positive relationships for the parents*

This factor refers to the support the parents of the disabled child receive [1]. This includes informal social support (relationships with friends, relatives and neighbours) and professional support.

*Barriers:* Parents often reported a lack of informal support, or perceived social isolation, and having to rely on formal support. They said they lacked information on available activities, support and legal rights. Parents often felt left alone by local professionals, as expressed in a communication between several mothers:

Elise: *'We are a really active family with two older siblings doing sports, and only he [her son with disability] cannot partake. And so I asked the paediatrician, 'Can you give me some tips?' and he was like, 'Just try to find out yourself.'"*

Mia: *'And they should know. It is not the first child with cerebral palsy they meet. Yet, it is my first child with CP – I don't have a clue what children with CP can do, or master.'*

Parents often perceived a lack of clear responsibilities between different professionals in their local setting.

*Facilitators:* Informal support from relatives or friends was perceived as a major facilitator. One parent explained this concerning downhill skiing:

Victoria: *'Sitting downhill skiing. We are not experienced in downhill skiing and we don't have the possibility to learn. So it is difficult to find possibilities for my child to do it.'*

Researcher: *'How do you solve this challenge? Do you have an assistant or something like that?'*

Victoria: *'We have another family, our friends that are experienced in downhill skiing. They take my daughter with them and then bring her back to us.'*

Another important informal support for parents was the exchange with other parents in the same situation, such as during a rehabilitation intervention or in the local community or sports club.

Parents also talked about motivated local professionals as a significant support in finding the right activities for the children, including other therapists or sport clubs, and at times advising against certain activities or settings based on their experience. These facilitating experiences could also often be extended to advocacy groups, such as user organizations.

Professionals named local Norwegian Labour and Welfare Administration (NAV) offices, and the appointed persons in charge of inclusion in the local municipality, as facilitators.

## Discussion

The purpose of this study was to explore and describe key barriers and facilitators for participation in leisure activities for children and youth with disabilities in Norway. The framework, provided by King et al. [1] has proven to be an adequate tool to use when structuring and analyzing the collected data. Consequently, In this study, there were no aspects of the data that could not be structured and analyzed using this model.

The results show that a methodological approach including children, parents and professionals provides different perspectives. The focus of professionals was the children–parent relationship, combined with physical and institutional aspects, influencing participation in leisure activities. For example, the family engagement and different supports connected to the Norwegian welfare model. This is in line with the finding of other researchers that included the perspective of professionals or clinicians [27,28]. As the clinicians interviewed by Wright et al. [27], professionals in this study were able to both reflect on their point of view and put themselves in the perspective of the children and youngsters they worked with. The parents focussed on the child's abilities, peer relationships and equal participation for their child, and formal and informal support for the child, themselves and the whole family. The participating children's attention was on positive aspects of participation, such as participating in preferred and enjoyable

activities and being with friends and less on what might inhibit their participation. As Jaarsma et al. [28] showed in their study in the Netherlands, children focussed mostly on fun, peers as facilitators.

The results have shown that both facilitators and barriers vary between individuals and are often tributary to the setting they live in. As many authors have observed, several factors can be seen as both facilitators and barriers, depending on the individual and the situation [7,9,17,24,26–28].

### Child factors

Increasing age was found to work as barrier for subdimensions within child factors. The participation gap increased between children with and without disabilities with increasing age, where low motivation, low self-esteem or even dropout from the leisure activity were experienced by parents of children with disabilities. This supports the results of many other studies [26,39,40]. Strategies to work around own restrictions – called 'masquerading' in a recent scoping review by Krieger et al. [11] on the participation of adolescents with autism spectrum disorder. Such 'masquerading' strategies were used by some of the children in this study, when choosing activities making their disability invisible and participating within the activity according to their capabilities.

An important factor restricting the child's participation mentioned by parents and professionals was the general level of energy of the child. Fatigue was one of the main barriers for participation. Fatigue as a barrier for participation has been reported in relation to many diagnoses [27,28,41–43], therefore, careful planning of the activities to be prioritized during a day is required.

The child's increasing wish for autonomy and independent participation with age was another challenge mentioned by parents and professionals in this study. This has also been reported by Dolva et al. [10] in their research on children and adolescents with Down syndrome in Norway. Internationally, this is a tendency also observed by Krieger et al. [11]. Jaarsma et al. [28] also have reported autonomy to be an important factor that was mainly reported by professionals and children in their study, while no parents reported on this barrier. In our study several parents reported this barrier, reflecting both on unpleasant situations that appear because of this barrier and expressing empathetic understanding to their child's wish for autonomy.

The child's own activity preferences were discussed intensively by parents and professionals. Beside the facilitating effect when following these preferences, they could also have a hindering effect, as reported by multiple studies [9], when preferences and planned activities were in conflict.

Overall child factors have been foremost characterized as barriers in previous research, besides the child's preferences [9]. This study could show that a positive attitude (e.g. adapting rules) and a focus on opportunities (e.g. finding 'niches' within the activity) could bring forward more facilitating strategies. This was most apparent in the group of children. While in other studies [27,28] children reported their own disability or health as limitations, the participating children in our study never mentioned their own disability as a barrier. However, they mentioned other children's disability as possible limitations for participation in certain activities. It is not clear if this is a general tendency in Norway, or if this is due to the child's age, which was significantly lower in other studies [27,28]. There is a chance that the participants of this study were – due to their younger age – not capable to reflect on their own participation limitations. Another explanation may be the sample of children- all participating in an intensive rehabilitation programme focussed on adapted physical activities and the child's possibilities. The children's participation in the rehabilitation programme may have given them activity competences and a sense of success to overcome barriers.

### Family factors

Family factors were often seen as 'either-or' factors by the parents and professionals of this study. Examples were discussions about the effect of an active versus an inactive family environment. This supports the results of other studies [7,11,12,27,28,44].

Another major factor mentioned during the interviews was time. Time has also been mentioned as a main barrier by other authors [9,26,39,40]. In this study, time was related to the financial and time impact on the family (e.g. longer distances to suitable activities, increased need for support during participation), family demographics (e.g. the parents' level of employment and working hours), and home environment (e.g. coordinating everyday life and activities in the family), all in line with the conceptualization by King et al. [1]. Financial aspects were mostly mentioned in situations where families did not receive support from the Norwegian welfare state or needed

expensive one-to-one support during participation in leisure activities. As in the study from Wright et al. [27] financial aspects were mostly mentioned by adults. Children, on the other hand did not mention financial limitations. Contrary to Rimmer et al. [7], financial constraints paid a much lesser role in the present study. Factors like paying club-memberships were not perceived as barriers. Only expenses that were more or less directly related to the child's disability (e.g. special equipment, additional support) were perceived as barriers. This could be a result of generally lower membership-fees in Norway, for example for the participation in sports-clubs; at least in a European comparison [45,46].

### Environmental factors

Environmental factors varied the most between being facilitating or hindering, according to the interviews with parents and professionals. While some parents experienced a supportive and adapted environment, others met many barriers to the child's participation in leisure activities. Moreover, parents and professionals identified a difference in the physical and institutional environment, when comparing urban and more rural areas. Rural areas were associated with longer distances to suitable activities or institutions, and generally little variety of available activities. This is in agreement with Rimmer et al. [7] and Shields et al. [9]. Unfortunately, this study did not collect data on whether the participants lived in urban or rural areas, so that the collected information could not be specially reviewed in light of their place of residence.

Additionally, professionals experienced parents themselves to be either facilitating or hindering to the child's participation, depending on their engagement in the specific leisure activities. Parents supporting their children to participate in leisure activities, mentally, emotionally and physically, had a large facilitating effect while parents with less engagement were perceived as a barrier. While parents with less engagement or with a dictating attitude were perceived as a major barrier, according to the professionals. This family factor has previously been reported in different studies [11,27,28].

There was a consensus in the interviews of parents and professionals that policy restrictions were not that apparent in Norway. However, they mentioned multiple supports offered by the Norwegian welfare state that facilitated participation in leisure activities for children and youth with disabilities. This agrees with Ullenhag et al. [14], who referred to Norway as a state with generous policy towards including individuals with disabilities, compared to other European countries. Barriers within legislation were mostly reported on a local level in this study. Moreover, a European research project on the policies and characteristics for sports clubs discuss facilitating policies and structures in Norway, like supporting and strengthening voluntary work [45]. Anaby et al. [44] also saw bureaucracy as one reason for segregation and thereby a barrier to equal participation in their scoping review. It seems that in general, Norwegian policies also support participation and lower barriers not just for non-disabled, but also for disabled children.

Parents had an important function in the child's participation in leisure activities, and Krieger et al. [11] describe this as an 'anchoring' function. This is also in agreement with other studies [26,40]. Other supporting relationships for the children, expressed by parents and professionals, were leisure assistants, or activity leaders with a positive attitude towards inclusion. This is in line with both Shields et al. [9] and Krieger et al. [11]. For children, positive peer relationships were the most important factor for their participation. Social acceptance and positive relationships to peers have also been reported as one of the main facilitators from the perspective of children and adolescents with disabilities in other studies [27,28].

In regard to the environmental factor of the importance of relationships for the parents, information varied considerably. While some experienced a lot of formal and informal support from relatives and professionals in their community, and had information easily accessible, others experienced significant struggles. Most variation was expressed in regard to knowledge, motivation and commitment of local professionals such as paediatricians, occupational therapists, or welfare workers and the collaboration between these service providers. This is common with the results of Rimmer et al. [7], who found a lack of information or lack of knowledge and commitment from professionals as barriers to participation. The most facilitating relationship for the parents was with other parents of other children with disabilities. Wright et al. [27] describe clinicians as a missing link to support an active lifestyle, participation and behavioural changes. This underlines the importance of motivated and knowledgeable professionals, also found in this study.

The present study must acknowledge some limitations. One is the limited number of child and youth participants, due to recruitment difficulties. Multiple

authors have discussed the challenges that come with interviewing children [36,47,48], especially within the additionally vulnerable demographic of children with disabilities, which this study tried to take into consideration. In regard to the children's age, Docherty and Sandelowski [47] argue that children (in general) at the age of six have the cognitive and language abilities to be interviewed. This might not apply for all children in this group, especially those with learning disabilities, which needs to be taken into consideration as discussed by Lewis and Porter [36] and stated in article 12 of the UNCRC [29]. In this study, children were aged between eight and 11 years, which seemed at times somewhat too young. Other studies, that included the perspective of children and youth [27,28], generally worked with a sample with a higher age. Although saturation was reached with the current sample the question stands, if an older sample could lead to more perspectives.

Another limitation was the cooperation with a single rehabilitation institution. Since the cooperating institution focussed mainly on adapted physical activity, participants, including parents, children and professionals, also focussed during the interviews mainly on physical activities and took some time to include other leisure activities in their considerations. Moreover, since the interviewed parents and children already had been involved in an intervention and thereby committed to their participation in leisure participation, they – especially the parents – might already fall into the group of an active and involved family environment. This possibly could have affected their reflections on barriers and facilitators and their own role. Therefore, it might be wise for future studies to include parents and families that might not be as much committed to active participation or increasing participation.

A third limitation was the dominance of female participants in the interviews with parents. During analysis, it became clear that fathers often brought a slightly different, more pragmatic and practical perspective to the interviews, while mothers focussed more on relationships, experiences and emotions connected to participation in leisure activities. A more balanced sample of male and female participants would be a point of improvement for further research. This was not the case with the professionals interviewed.

In conclusion, this study provides an overview of the main facilitators and barriers for participation in leisure activities for children and youth with disabilities in Norway. Facilitating and inhibiting factors are found to vary depending on the context, and may thus serve as both a facilitator and a barrier. Consequently, participation measurements need to be context specific.

The main findings of the present study are in accordance with international studies, and of significance to occupational therapy. However, a difference may be the effect of the Norwegian welfare system, compensating for many financial barriers experienced in other countries. Thus, when developing a new instrument to measure participation in leisure activities in a Norwegian context this must be taken into consideration.

Future studies in the Norwegian context should evaluate these factors on a larger scale in order to achieve more generalizable results. Among others, studies could look at the differences between urban and rural areas in more depth in order to identify strategies to facilitate participation in all settings. Finally, involvement of children and youth with disabilities in future studies is of greatest importance in understanding their perspective of participation opportunities and wishes.

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## Disclosure statement

The authors report no conflict of interest.

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Article 3

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*Article*

# Testing ActiveYou II: Applying Cognitive Interviews in Improving Item Quality and Applicability of a Web-Based, Self-Report Instrument on Participation in Children with Disabilities

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**Abstract:** Background: Children and youth with disabilities participate less in leisure activities than their nondisabled peers. Increasing participation is a primary goal of rehabilitation interventions. However, valid measures that include the individual's perspectives and facilitating and hindering factors for participation are lacking in the Norwegian setting. In this study, ActiveYou II, a self-report, web-based instrument under development, was tested to obtain item quality and applicability. Methods: Nine children with disabilities participated in cognitive interviews, testing a first set of ActiveYou II items. The verbal probe method for cognitive interviews was applied. Results: The children's comprehension and responses through cognitive interviews improved the applicability and item quality of ActiveYou II. Item adjustments were made to the wording of the questions and response alternatives, and the number of response alternatives were decreased where appropriate. Conclusion: The use of cognitive interviews with children before performing further psychometric testing has been very useful in the development process of ActiveYou II. Adjustments of the questions and response alternatives were made accordingly.

**Keywords:** children with disabilities; participation; instrument development; cognitive interviews; self-reported; rehabilitation

## 1. Introduction

Increasing participation in leisure activities is one of the major goals and outcomes of rehabilitation interventions for children and youth with disabilities [1-3]. This is grounded in an understanding of the positive effects of participation in leisure activities for the physical, emotional, and social development of children and their general well-being [4-6]. Valid and reliable instruments are needed to gain an increased understanding and knowledge of the participation patterns in leisure activities shown by children with disabilities and for planning and evaluating interventions [6,7]. In their systematic review, Adair et al. [6] argued that measures continually need to be adapted to be in accordance with the developing understanding of the participation construct. Furthermore, they promote bringing more of the individual's subjective perspectives on participation into measures. Moreover, measures need to be appropriate for specific settings and regions,

since factors influencing participation may vary between national and international settings [8,9].

To date, there is no valid web-based measure of participation for the Norwegian setting based on the child's self-report, nor instruments that measure facilitating and hindering factors for participation. Prior studies have tested and validated Norwegian versions of Preferences for Activities for Children (PAC) and Children's Assessment of Participation and Enjoyment (CAPE) [10,11]. However, the activities and items did not quite fit the Norwegian setting. There were also difficulties in administering the instruments, especially for children with intellectual disabilities [10]. Most crucially, the publisher of CAPE and PAC declined to publish the Norwegian versions due to the small market. Participants also wished for questionnaires that could be administered digitally [10]. Therefore, the self-reported and web-based questionnaire ActiveYou I (Norwegian: AktiveDeg I) was developed [12]. ActiveYou I measures a child's activity preferences for participation in 17 different physical leisure activities [12]. At present, the companion measure, ActiveYou II (Norwegian: AktiveDeg II), is under development. ActiveYou II aims to evaluate current patterns of participation in different physical leisure activities, including individual experience and perceived facilitating and hindering factors. Both instruments are intended to be used to plan and evaluate rehabilitation interventions, focusing on participation in adapted physical activities [12]. However, both ActiveYou I and II are intended to be generic, and the activities can be changed according to different contexts and target groups [12].

In the International Classification of Functioning, Disability and Health (ICF), participation is defined as "involvement in life situations" [13]. However, there has been criticism of the definition given in the ICF, mainly regarding the lack of subjective perspectives on participation and the lack of clarity in the distinction between activity and participation [3,14]. Based on previous theoretical work, such as the family of Participation Related Construct model (fPRC) by Imms et al. [3], participation is defined as a multidimensional construct that describes both observable (objective) and unobservable (subjective) components that contribute to a person's participation in life situations. According to King et al. [15], context includes personal, family, and environmental factors. Observable components are mainly attendance, participation frequency, diversity, and the social and physical context. Unobservable components are the individual's cognitive (self-regulation, relevance for future endeavors, personal goals, autonomy) and/or affective engagement (feelings of identification and/or belonging, in relationship with adults and peers) [16]. This is the theoretical fundament of the development of ActiveYou II.

The aim of this study was to evaluate the item quality and applicability of ActiveYou II. The study explored the following questions: (i) Can cognitive interviews with children and youth (target group) improve item quality and applicability of ActiveYou II? (ii) Which adjustments are needed before advancing in the development process of ActiveYou II?

## 2. Methods

### *2.1. Participants and Procedure*

Participants in the cognitive interviews were nine children within the target-group recruited from a rehabilitation center in Norway. The inclusion criteria were (1) school age (6–17), (2) ability to give informed consent, and (3) having the ability to understand and to communicate verbally and participate actively in the interviews in Norwegian. Thus, children with moderate/severe intellectual disability were excluded. Since ActiveYou II was supposed to be an instrument for a wide target group, it was deemed to have a sample of participants that represent different parts of this target-group.

Recruitment and data collection took place in November 2018. Children and their parents were informed about the purpose of the study, and information and consent forms

were handed out to potential participants. Participation in the interviews was voluntary and had no effect on the participants' intervention at the center. Parents could attend the interviews to observe or assist their children if they wished.

The verbal probe method was used, as recommended by Spencer et al. [17]. The first and last author designed an interview guide based on questions and formulations they expected would be difficult for the children. Interviews took place in small groups of a maximum of five children and lasted approximately 30 min. During the interviews, the questions being discussed were shown via a projector. The children were asked about general phrasing and understanding of the items and design, and the children were asked to identify individual words that seemed strange to them. The children were also asked to express themselves openly if any other part of the questionnaire seemed confusing or difficult to understand. In addition, all children received a paper copy of the questions, on which they could note their answers. The interviews were recorded through both a voice recorder and video. Potential issues of privacy and ethics were approved by the Norwegian Centre for Research Data (reference number 52305/3/STM).

### 2.2. *ActiveYou II*

ActiveYou II aims to be a self-reported, web-based instrument to capture children's and youths' patterns of participation in physical activities. Figure 1 gives an overview of the whole development process of ActiveYou II thus far. In the process of developing ActiveYou II, group interviews with children, parents, and professionals were conducted to identify important facilitators and barriers for participation in leisure activities that should be included in the instrument [18]. Since ActiveYou II is supposed to be self-reported, it was deemed important to include the perspective of children and youth in the interview process. Children and youth with disabilities are expected to administer it themselves or with assistance from a caregiver. To answer, participants log into a password-protected homepage. The questionnaire can be administered from any device that supports standard internet browser applications. The 17 activities included are: pool activity, cross-country skiing, horseback riding, training in a fitness room/center, downhill skiing, climbing, outdoor activities, water activities outdoors, playing in the snow, going for a walk/hiking, gaming for training (e.g., Happy Rehab, Wii Sports, Let's Dance…), rolling activities, move to music, group activities, play outside, cycling, individual activities. All activities are visualized for the children using a short slideshow of three photos that show the activity at hand with different performance modes with and without assistive activity devices. For each activity, children are asked about (1) their frequency of attendance, (2) with whom they participate, (3) their sense of mastery, (4) their level of involvement/attraction, (5) facilitating personal, familial, and environmental factors, and (6) hindering personal, familial, and environmental factors, before moving to the next activity.

Table 1 gives an overview of the items and the amendments made during the different phases of the study. Sense of mastery is defined as "the extent to which one regards one's life chances as being under one's own control" [19]. Involvement is defined in line with leisure research as "an unobservable state of motivation, arousal, or interest with respect to a recreational activity or associated product" [20] The items covering involvement in the questionnaire (e.g., Is it fun to do the activity?; The activity is important for me) were taken from the Modified Involvement Scale designed by Kyle et al. [21], specifically the dimension of attraction, which includes the individual's perceived importance, preference, and pleasure towards a specific activity [21].

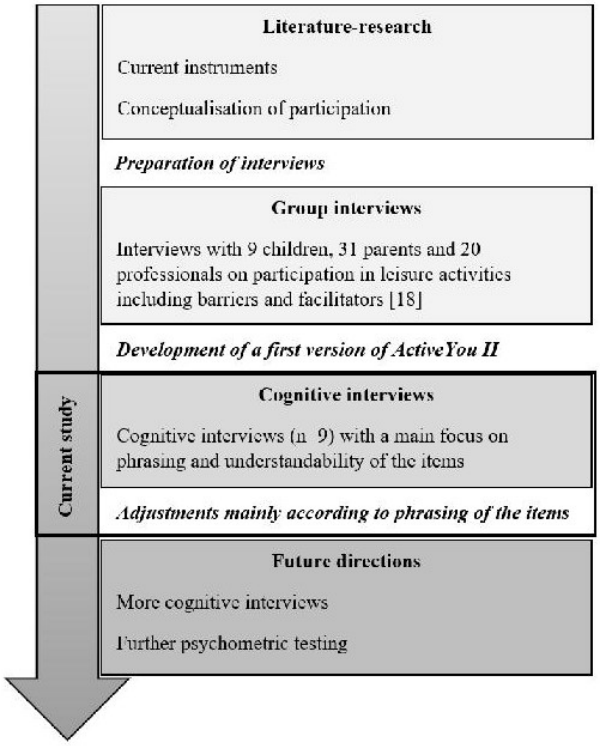


**Figure 1.** Flow-chart of the whole development process of ActiveYou II.

**Table 1.** The order of the items of ActiveYou II before and after the cognitive interviews.

| Item | Cognitive Interviews | Adjustments for Further Development |
|---|---|---|
| 1a | How often have did you do this activity during the last three month?<br>• 3–7 times a week<br>• 1 or 2 times a week<br>• 1 or 2 times a month<br>• Never | How often do you do this activity?<br>• 3–7 times a week<br>• 1 or 2 times a week<br>• 1 or 2 times a month<br>• Never |
| 1b | Are you satisfied as it is?<br>• Yes<br>• No | Is this as often as you like it?<br>• Yes<br>• No |
| 2a | With whom do you do the activity<br>• Alone<br>• With family (parents, siblings)<br>• With other relatives<br>• Sports club, community-center, youth-club<br>• Self-organized with friends<br>• With a personal assistant, leisure assistant… | <br>• Alone<br>• With family<br>• With personal or leisure assistant<br>• With other adults<br>• Sports club, community-center, youth-club<br>• With friends<br>• Together with other kids at school |
| 2b | Are you satisfied as it is?<br>• Yes<br>• No | Do you like it that way?<br>• Yes<br>• No |
| 3 | How good do you think you can do the activity?<br>Smileys<br>• Negative | Smileys<br>• Negative |

| | | |
|---|---|---|
| | • Neutral<br>• Positive | • Neutral<br>• Positive |
| 4 | It is fun to do this activity.<br>Smileys<br>• Positive<br>• Neutral<br>• Negative | Smileys<br>• Negative<br>• Neutral<br>• Positive |
| 5 | The activity is important to me.<br>Smileys<br>• Positive<br>• Neutral<br>• Negative | |
| 6 | This makes it easier for me to participate<br>• Somebody tells me where I can participate<br>• Activity available close by<br>• Participation is free<br>• Participate together with family<br>• Participate together with friends<br>• Mom, dad, or siblings assist me<br>• I have a personal assistant or leisure assistant<br>• The activity-leader adapts the activity<br>• I experience no pain<br>• I have the equipment I need | • I can participate together with my family<br>• I can participate together with friends<br>• Mom, dad, or siblings assist me<br>• I have a personal assistant or leisure assistant<br>• I have the equipment I need<br>• I can do the activity where I live<br>• Participation is free<br>• The other children at the activity are nice to me.<br>• The adults at the activity help me |
| 7 | This makes it difficult for me to participate<br>• I don't know if there are possibilities to participate<br>• Activity not available where I live<br>• Too far away<br>• The date does not work for me<br>• Too expensive<br>• Nobody can assist me<br>• The others aren't nice to me<br>• The activity-leader does not take care of me<br>• I'm too exhausted | • I don't have the equipment I need<br>• Activity not available where I live<br>• The date does not work for me<br>• Too expensive<br>• Nobody can assist me<br>• The other children aren't nice to me<br>• The adults at the activity do not help me<br>• I'm too exhausted<br>• I experience pain<br>• I feel insecure<br>• There is nothing that makes it difficult for me to participate |

### 2.3. Cognitive Interviews

The method is a form of qualitative data collection, in which the researcher goes through the instrument under development with an individual or group of participants for whom the instrument is designed. It is a verbal response method on items with the purpose of enhancing the understanding and meaning of the instrument [22]. During the interview, the researcher asks the informant(s) to speak out their thoughts on the phrasing of the items, their understanding of the meaning of the items, and their approach to responding [17,22]. According to Spencer, Bouffard, and Watkinson [17], this method is closely based on Tourangeau's question-and-answer model developed in cognitive psychology [23]. Based on this theory, the individual has to complete four actions to answer the questions: (1) comprehension, which involves the individual's understanding of the question; (2) retrieval, which involves the individual accessing memories and information relevant for the question; (3) judgment, which involves forming an answer to

the given question based on the retrieval; and (4) response, which refers to the process of relating one's answer to the given response categories.

This method is helpful in identifying discrepancies within the instrument in order to make adjustments for the targeted population before proceeding with further testing on larger samples [17,24]. There are two different approaches to cognitive interviews—the "think aloud" and "verbal probe" methods [22]. Using the think aloud method, the participant freely expresses his thought-process while answering the questionnaire, and the researcher takes a more passive/observant position. On the other hand, in the verbal probe method, the researcher takes a more active position by asking the participants about specific aspects of the questionnaire based on a previously designed interview-guide.

Cognitive interviews have shown to be efficient in instrument development [17,24]. When applying cognitive interviews with children, the verbal probe method is recommended [17]. Within healthcare and rehabilitation, Liljenquist et al. [25] described how the development of the Participation Experience Survey (PES) benefited from implementing cognitive interviews in the process of measure development. Spencer, Bouffard, and Watkinson [17] have discussed and tested cognitive interviews with children with disabilities in a setting focused around adapted physical activities. They used cognitive interviews to validate established instruments on the individual's perception about their own athletic performance. In the development of ActiveYou I, Dalen et al. [12] also applied cognitive interviews with children.

### 2.4. Data Analysis

The qualitative data from the cognitive interviews were coded directly in the audio files, and the thematic content analysis [26] was done with software support using MAXQDA [27]. Data were analyzed in relation to Tourangeau's question-answer-model applying the four categories: comprehension, retrieval, judgment, and response [23]. After meaningful parts were identified, the essence of these sequences was extracted and labeled relevant categories. Comprehension, retrieval, judgment and response appeared to be the operating categories. Some examples are presented in Table 2 to give transparency to the analysis-process. As understanding or not understanding a concrete item, reflections on the meaning, or even providing suggestions for alternatives were the practical outcomes of the analysis, the results are presented as a whole. Thus, the items of ActiveYou II are presented following the order of the questionnaire.

**Table 2.** Examples of the analysis process.

| Original Quote | Extraction | Conceptual Theme |
| --- | --- | --- |
| Interviewer: «How often do you go to the pool<br>Child: «I go there every other Friday.»<br>Interviewer: «Alright. What answer-alternative do you think you should cross than?»<br>Barn: «I don't know.» | Item 1a: The child is able to formulate an answer to the question but cannot translate the answer to the given categories in the questionnaire. | response |
| Interviewer: «Do you think there is a difference between these three questions?» (refer to items 3, 4 and 5)<br>Child: «No.» | Items 3, 4, 5: The child cannot distinguish between the meaning of the items 3, 4 and 5 | comprehension |

## 3. Results

### 3.1. Characteristics of the Sample

Nine children participated in the cognitive interviews: two males and seven females, with a mean age of 12.6 years (SD = 1.1 years). Four had a physical disability, three had mild intellectual disability, and two had a complex disability. Five parents participated in the interviews to assist their children and give their perspectives.

### 3.2. Item Adjustments Based on the Cognitive Interviews

The analysis of the cognitive interviews showed several issues with the general phrasing of the questions or specific terminology, which lead to complications in the comprehension-phase of the question-answer-model. To clarify the results, Table 1 shows the items before and after the cognitive interviews. The formulations have been translated from Norwegian into English as close to the original as possible. The results are presented in the same order that they appear in the instrument, to keep the structure of the section close to the data collection procedure and the instrument.

Generally, it became clear that parents, interviewers, or both were needed to assist the children with intellectual disorders in answering the questions, especially when there were multiple alternatives to choose from. Regarding the frequency of attendance (item 1a/b), some children had problems finding the right category. When asking how often they did an activity, they answered "I do this every other Friday" or "I do this on Mondays and Thursdays." They were more used to working with weekly schedules—as several parents explained—than thinking in quantitative categories like 1 or 2 times a month or 1 or 2 times a week. Some children did not understand the additional question Are you satisfied as it is? After explaining the intent of the question, the children suggested a formulation like "Is this as often as you like it?", "Is it OK as it is?", or "Do you like it as it is?"

The second item on context (*With whom do you do the activity?*) also showed several problems regarding comprehension, specifically with specific terminology. For example, the children expressed difficulties with understanding or explaining the terms *relative* or *self-organized*. Participating parents suggested that *other adults* might be easier to understand than relatives for the children.

Regarding response alternatives, children and parents explained that children often did activities together with other children at school: not during lessons, but unorganized activities during breaks or before and after school using the school facilities. Therefore, they wished for another response alternative: *"with others at school"*. Similar to item 1b (*Are you satisfied as it is?),* children expressed their difficulties with item 2b (*Are you satisfied as it is?).* Here, participants suggested a formulation like *"Do you like it that way?"*

Regarding the items on the subjective (unobservable component) sense of mastery (*How good do you think you can do the activity?*) and involvement/attraction (*Is it fun to do this activity? The activity is important to me*), children had no problems responding using the three-point Likert scale that consisted of a green (smiling), a yellow (neutral), and a red (negative) smiley face. However, children could not differentiate between the meaning/intent of the three items. When asking about their comprehension of why participation was important to them (regarding the question *Is the activity important to you?*), the children often answered, *"Because it is fun,"* which is much more an indicator for the question *Is it fun to do this activity?* When asked directly if they saw a difference between the three items, the majority of the children said *"No"* or could not explain what the difference might be. Some parents, who assisted their children, tried to explain that an activity might be important for them in order to train certain skills, improve their mobility, or improve their overall health. Therefore, it might be important even though they were not enjoying the activity that much. Still, this was not the children's comprehension of the items.

Regarding the facilitating (item 6) and hindering factors (item 7), children were overwhelmed with the number of response alternatives. Again, children struggled with comprehension of different formulations and terminology. For example, *Activity available close by* was experienced as too vague. After explaining the meaning to the children, they suggested "I can do the activity where I live." Furthermore, the formulation *The activity leader adapts the activity* was hard to comprehend for the children since both *activity leader* and *adapt* were unknown terms for the children. After explaining the meaning to the children, they suggested "The adults at the activity help me." Regarding the financial costs of the activity (e.g., participation *for free* as a facilitator or *too expensive* as a barrier), children often had insufficient knowledge of the costs, especially if the costs might have been a barrier. This was something that only parents could relate to. Furthermore, children had problems with the formulation *I have the right equipment*. Here, children and parents suggested the alternative "I have everything I need."

## 4. Discussion

### *4.1. Adjustments to the Instrument*

The results of the cognitive interviews for ActiveYou II showed that adjustments were needed to make ActiveYou II more applicable for children with disabilities. The involvement of children from the target group was crucial in this developmental process. The children's contribution was first and foremost connected to comprehension and response.

Many children felt it was difficult to deal with the number of response alternatives for the context, facilitators, and barriers. Even if they were able to make their judgment on the question, they had difficulties formatting their response into the given categories. This was based both on issues with terminology and the at times overwhelming number of answer alternatives. Therefore, it seemed appropriate to combine different alternatives or eliminate alternatives that did not seem relevant. Both the context and the facilitators and barriers need adjustments based on the children's suggestions (as shown in Table 1). Gustafsson et al. [28], in their testing of the Swedish ICECAP-O, and Liljenquist et al. [25], during the development of the PES, reported the benefits of including cognitive interviews in a mixed-methods approach to instrument development and testing. Additionally, the development process of ActiveYou I benefited from the application of cognitive interviews [12]. Spencer, Bouffard, and Watkinson [17] argued that cognitive interviews were an important addition to the validation process of self-report instruments for children with disabilities. Experience from the current study supports this argument. This approach is in line with the Convention of the Rights of the Child [29] and the Convention on the Rights of Persons with Disabilities [30]. Incorporating these methods more often could help bring forward the perspective of a group that otherwise is too easily just talked about and not talked with. In a focus group study with persons with disabilities, Hammel et al. [31] found that the participants wanted to be consulted for their opinion about their participation.

Regarding the discussion of the items that measured the children's level of involvement/attraction and sense of mastery, the cognitive interviews showed that the children had problems differentiating the intention/meaning of these items. Therefore, one of the three items (*The activity is important to* me) will be eliminated from the questionnaire. More in-depth research on the understanding of the remaining items (*How good do you think you can do the activity?* and *It is fun to do this activity)*, possibly through additional interviews with children who also complete the digital version of the questionnaire, is needed to adjust the items to the target group further. Liljenquist et al. [25] showed how implementing cognitive interviews in multiple stages of the development and validation process improved the applicability of the final instrument for the target group. This is an approach that could also be beneficial for the development of ActiveYou II. When involving children and youth, the target age is important. The target

group for ActiveYou II is age five to 17. However, the age of participants in the interviews ranged from 11 to 17. It is a limitation of the study that children 5 to 10 years of age were not included for practical reasons.

### *4.2. The Value of Cognitive Interviews in the Instrument Development Process*

This study shows the value of including children from the target group in order to adjust the instrument to their needs. The results showed issues with comprehension of both questions and different response-alternatives. Like the situation when the children were able to find relevant information to answer the given question (retrieval) about frequency of participation, and formulate an answer, but could not transform their response to the given categories. Addressing these issues will most likely help to improve the validity of the new instrument. Many of these issues might not have been discovered without the application of cognitive interviews. Like Spencer, Bouffard, and Watkinson [17], the authors of this study think that these methods should be used more often when designing or adapting instruments for children and youth with disabilities.

### *4.3. Limitations*

This study has some limitations. The main limitation might be the small sample and age range of the participating children. Since ActiveYou II is meant to serve a wide target group age 5 to 17 with different types of disabilities it would be an advantage to have participants with a broader age range for testing the instrument. Meanwhile, the sample at hand only covered children and youth aged 10 to 14. Still, with a variety of impairments, they represent a broad target group. The sample covered more girls than boys. Gender differences may, however, not be of great importance, when it comes to comprehension of wording of questions.

## 5. Conclusions

In conclusion, the current study showed how cognitive interviews with the target group can improve item quality and applicability of ActiveYou II. They identified the adjustment needed regarding unclear, difficult items on wording, formulations, amount, or different response alternatives. Furthermore, they provided new, adjusted or meaningful suggestions, and even suggested eliminated irrelevant items. In this way, cognitive interviews enhanced the development of ActiveYou II Therefore, this study can promote the approach of applying cognitive interviews–especially in combination with Tourangeau's question-and-answer model–when designing instruments targeted at children and youth. Based on this study, the most relevant aspects of the question-answer-model are comprehension and response. Therefore, these two aspects should be considered carefully in the instrument-development process. Further new cognitive interviews could be useful in order to evaluate the effect of the adjustments done after this study. In addition, these interviews should include participants representing the whole age range of the target group of ActiveYou II.

At the same time, the results pointed out a direction for the further developmental process. Before ActiveYou II can be implemented, the psychometric proprieties need to be determined in future studies. This includes an adjustment to the recruitment of participants and appropriate methods for psychometric testing of the web-based instrument, such as test-retest reliability and internal consistency, in addition to construct validity and sensitivity to change.

**Author Contributions:** Conceptualization F.S.; methodology F.S. and A.U.; formal analysis F.S., A.-S.D. and A.U.; writing—original draft preparation F.S.; writing—review and editing R.J., A.-S.D. and A.U.; supervision R.J., A.-S.D. and A.U.; project administration F.S. All authors have read and agreed to the published version of the manuscript.

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**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study.

**Data Availability Statement:** The data are not publicly available due to data-privacy regulations, but can be available on reasonable request.

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# Appendix

## A Information and consent letters

### A1 Group interviews - children

**Forespørsel om deltagelse i forskningsprosjektet**

***«BARNAS II»***

**Bakgrunn og formål**

Å være med i fritidsaktiviteter hjemme der du bor er både viktig og gøy. Men, det er kanskje ikke alltid mulig at du få holde på med det du ønsker mest. Det kan være ulike årsaker til det.

På Beitostølen Helsesportsenter arbeider vi for at alle barn skal få mulighet til å holde på med fritidsaktiviteter. Du husker kanskje at du var med og fylte ut et spørreskjema på nett før du har kommet til Beitostølen, da du spurt om hvilke aktiviteter du hadde lyst å være med under mens du var her. Dette spørreskjemaet kaller vi 'BARNAS I' og dette har hjulpet oss masse for å planlegge aktivitetene på Beitostølen, slikt at du skulle ha det gøy. Nå vil vi gjerne utvikle ett nytt spørreskjema, for å finne ut hva du og andre barn driver med i fritiden hjemme. For å lage et spørreskjema som er enkelt å bruke og ikke tar alt for langt tid til å fylle ut trenger vi litt hjelp av deg.

**Hva betyr det å bli med?**

Mens du er på Beitostølen vil jeg snakke med deg og en gruppe av andre barn om hvilke aktiviteter dere holder på med i fritiden hjemme og hva som gjør det gøy for dere å være med. Vi skal også snakke om ting som gjøre det lettere eller vanskeligere å være med. Samtalen kommer til å ta ca. 45 minutter vil bli gjort en ettermiddag når du er på Beitostølen. Det kan være vanskelig for meg å huske alt du og de andre forteller meg, så jeg vil gjerne ta opp samtalene våre på video. Hvis du vil ha en voksen med deg mens vi snakker sammen er det helt greit.

For å vite litt bedre hvem som er med i intervju ber jeg deg også om å fylle ut et lite spørreskjema på forhånd som tar maksimalt 10 minutter

**Hva skjer med det du forteller meg?**

Det du forteller meg skal ingen andre få vite. Videoopptakene skal bare være 'huskelapper' for meg og ingen andre skal se dem. Når jeg bli ferdig med studien skal video- og lydopptakener slettes.

**Frivillig deltagelse**

Det er frivillig å delta i studien, og du kan når som helst si ifra hvis du likevel ikke vil være md uten å behøve å si noe om hvorfor. Om du vil delta i studien eller ikke vil ikke ha noe innvirkning på ditt behandlingstilbud på helsesportsentret.

Hvis det er noe du lurer på kan du eller foreldrene dine tar kontakt med meg (Friedolin Steinhardt).

Med vennlig hilsen

Friedolin Steinhardt
e-post: friedolin.steinhardt@inn.no
tlf. 94050619

For spørsmål er det også mulig å kontakte:
Førsteamanuensis Høgskolen i Innlandet, Anne-Stine Dolva, anne-stine.dolva@inn.no, tlf. 61288024
eller
Forskningsleder Beitostølen helsesportsenter, Reidun Jahnsen, reija@ous-hf.no, tlf. 23026986

## Samtykke til deltagelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta
Navn: _____

---

(dato, signering deltager) (dato, signering foreldre/foresatte)

## A2 Group interviews - parents

# Forespørsel om deltagelse i prosjektet

*«BARNAS-II»*

**Bakgrunn og formål**

Barns deltagelse i fritidsaktiviteter er viktig. Det åpner muligheter til å lære seg nye ferdigheter, bli kjent med andre, det er gøy og har vist seg å være bra for helsen. På Beitostølen Helsesportssenter brukes et digitalt spørreskjema «Barnas I» som kartlegger hvilke aktiviteter barnet ønsker å delta i under opphold. I dette spørreskjemaet rangerer barna aktiviteter ved hjelp av smilefjes, surt eller nøytralt fjes. Dette har vi god erfaring med. Men, når det gjelder å støtte opp om barnets deltagelse i fritidsaktiviteter på hjemstedet finnes det ikke noe tilsvarende strukturert spørreskjema for å få identifisere ønsker, behov og muligheter. Det er kjennskap til slike forhold som er av betydning når en skal undersøke muligheter for deltagelse og eventuelt behov for tilpasninger og tilrettelegging for barn og unge med funksjonsnedsettelser i fritidsaktiviteter der de bor.

Målet med denne studien er å utvikle et digitalt spørreskjema «Barnas II» som barn og unge selv og/eller sammen med foreldre/foresatte kan bruke for å uttrykke opplevelser, ønsker og muligheter for deltagelse i fritidsaktiviteter i lokalmiljøet hjemme. For å utvikle «Barnas II» trenger vi innspill fra foreldre/foresatte og fra barna selv i tillegg til å dra nytte av forskning på området. «Barnas II» skal være til hjelp for å kunne «skreddersy» muligheter for deltakelse i fritidsaktiviteter for det enkelte barn i deres eget miljø, og bidra til å fange opp og følge opp endringer over tid. Siden det ikke finnes noe tilsvarende i Norge, vil «Barnas II» være nyttig på landsbasis der en er opptatt av fritidsaktiviteter for barn med funksjonsnedsettelser.

Studien gjennomføres i samarbeid mellom Høgskolen i Innlandet (tidligere Høgskolen i Lillehammer – hovedansvarlig) og Beitostølen Helsesportssenter. Den er knyttet til et doktorgradsprosjekt som utføres av Friedolin Steinhardt. Han har jobbet på Beitostølen Helsesportsenter, men er nå stipendiat ved Høgskolen i Innlandet.

**Hva innebærer deltagelse i studien?**

Deltagelse i prosjektet innebærer at du som forelde/foresatte deltar i et gruppeintervju sammen med fem til åtte andre foreldre/foresatte under oppholdet på Beitostølen helsesportsenter, mens barna er i aktivitet. Intervjuet vil komme til å vare ca. 45 til 60 minutter. Tema i intervjuet vil være 'deltagelse' – hvordan dere forstår deltagelse, hvilke aktiviteter hjemme og i lokalmiljøet er viktig eller favoritter for barnet og hvilke faktorer fremmer eller hemmer deltagelse. Før gruppeintervjuet vil vi be deg fylle ut et kort spørreskjema som vil ta ca. 10 minutter.

**Hva skjer med informasjonen om deg?**

Alle personopplysninger vil bli behandlet konfidensielt, og dataene vil bli anonymisert. Lyd og video-opptak fra intervjuet blir kun brukt i forskningsprosessen, og blir ikke vist til andre. Etter prosjektet er avsluttet ble alle video- og lydopptakene slettet.

**Frivillig deltagelse**

Deltagelse er frivillig, og du kan når som helst trekke ditt samtykke tilbake uten å oppgi noen grunn. Siden det er barna det gjelder er det viktig at disse er informert og enige i deltakelse i studien. Om du vil delta i studien eller ikke vil ikke ha noe innvirkning på ditt behandlingstilbud på BHSS.

Studien er tilrådd av Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

Med vennlig hilsen

Friedolin Steinhardt

e-post: Friedolin.Steinhardt@inn.no
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For spørsmål er det også mulig å kontakte:
Førsteamanuensis Høgskolen i Innlandet, Anne-Stine Dolva, anne-stine.dolva@inn.no, tlf. 61288024
eller
Forskningsleder Beitostølen helsesportsenter, Reidun Jahnsen, reija@ous-hf.no, tlf. 23026986

**Samtykke til deltagelse i studien**

Jeg har mottatt informasjon om studien, og er villig til å delta

Navn: _____

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(dato, signering deltager) (dato, signering barn/unge)

## A3 Group interviews - professionals

### Forespørsel om deltagelse i forskningsprosjektet
### *«BARNAS II»*

**Bakgrunn og formål**
Barns deltagelse i fritidsaktiviteter er viktig. Det åpner muligheter til å lære seg nye ferdigheter, bli kjent med andre, det er gøy og har vist seg å være bra for helsen. På Beitostølen Helsesportssenter brukes et digitalt spørreskjema «Barnas I» som kartlegger hvilke aktiviteter barnet ønsker å delta i under opphold. Dette har vi god erfaring med. Men, når det gjelder å støtte opp om barnets deltagelse i fritidsaktiviteter på hjemstedet finnes det ikke noe tilsvarende strukturert spørreskjema for å få identifisere ønsker, behov og muligheter. Det er kjennskap til slike forhold som er av betydning når en skal undersøke muligheter for deltagelse og eventuelt behov for tilpasninger og tilrettelegging for barn og unge med funksjonsnedsettelser i fritidsaktiviteter der de bor.

Målet med denne studien er å utvikle et digitalt spørreskjema «Barnas II» som barn og unge selv og/eller sammen med foreldre/foresatte kan bruke for å uttrykke opplevelser, ønsker og muligheter for deltagelse i fritidsaktiviteter i lokalmiljøet hjemme. For å utvikle «Barnas II» trenger vi innspill fra profesjonelle i tillegg til å dra nytte av forskning på området. «Barnas II» skal være til hjelp for å kunne «skreddersy» muligheter for deltagelse i fritidsaktiviteter for det enkelte barn i deres eget miljø, og bidra til å fange opp og følge opp endringer over tid. Siden det ikke finnes noe tilsvarende i Norge, vil «Barnas II» være nyttig på landsbasis der en er opptatt av fritidsaktiviteter for barn med funksjonsnedsettelser.

Studien gjennomføres i samarbeid mellom Høgskolen i Innlandet (tidligere Høgskolen i Lillehammer – hovedansvarlig) og Beitostølen Helsesportssenter. Den er knyttet til et doktorgradsprosjekt som utføres av Friedolin Steinhardt. Han har jobbet på Beitostølen Helsesportsenter, men er nå stipendiat ved Høgskolen i Innlandet.

**Hva innebærer deltagelse i studien?**
Deltakelse i prosjektet innebære at du skal deltar i et gruppeintervju sammen med andre ansatte ved BHSS. Intervjuet komme til å vare cirka 45 til 60 minutter og skal skjer i arbeidstid. Tema i intervjuet komme til å bli 'deltagelse' – hvordan dere forstå deltagelse, hvilken aktiviteter dere oppfatter som viktig, aktuelt for barn med forskjellige funksjonsnedsettelser og hvilke faktorer dere synes kunne fremme eller hemme deltagelse. I tillegg skal du utfylle et liten spørreskjema i forkant som komme vil ta ca. 5 minutter.

**Hva skjer med informasjonen om deg?**
Alle personopplysninger vil bli behandlet konfidensielt, og dataene vil bli anonymisert. Lyd og video-opptak fra intervjuet blir kun brukt i forskningsprosessen, og blir ikke vist til andre. Etter prosjektet er avsluttet ble alle video- og lydopptakene slettet.

**Frivillig deltagelse**
Deltagelse er frivillig, og du kan når som helst trekke ditt samtykke tilbake uten å oppgi noen grunn.

Studien er tilrådd av Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

Med vennlig hilsen

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anne-stine.dolva@inn.no, tlf. 61288024
eller
Forskningsleder Beitostølen helsesportsenter, Reidun Jahnsen,
reija@ous-hf.no, tlf. 23026986

## Samtykke til deltagelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta
Navn: _____

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(dato, signering deltager)

## A4 Cognitive interviews - children

### Forespørsel om ny deltakelse i forskningsprosjektet

### *Nytten av «BARNAS II»*

**Bakgrunn og mål**
Å være med i fritidsaktiviteter hjemme der du bo er både viktig og gøy, men det er kanskje ikke alltid mulig at du får holde på med det du ønsker mest. Det kan være ulike årsaker til det. På Beitostølen arbeider vi for at alle barn skal få mulighet til drive med de fritidsaktivitetene de har lyst til. Du husker kanskje at du var med og fylle ut et spørreskjema som heter «Barnas I» som handler om fritidsaktiviteter før du kom til Beitostølen. Vi lurer på om «Barnas II» kan være til hjelp for deg og andre barn for å få delta mer i fritidsaktiviteter. Derfor spør vi deg om du vil hjelpe oss å finne ut av det.

**Hva betyr det å bli med?**
Mens du er på Beitostølen vil vi som heter Friedolin og Lars Kristian snakke med deg en gang om hvilke aktiviteter du holder på med i fritiden din hjemme. Det kommer til å ta ca. 45 minutter. Da skal vi snakke om hvordan det er å fylleut Barnas II om aktiviteter du har holdt på med. Det kan være vanskelig for os å huske alt du forteller, så vi vil gjerne ta opp samtalene våre på video. Hvis du vil ha en voksen med deg mens vi snakker sammen er det helt greit.

**Frivillig deltakelse**
Det er frivillig å delta i studien, og du kan når som helst si ifra at du ikke vil likevel uten å si noe om hvorfor.

Hvis du lurer på noe kan du ta kontakt med doktorgradsstipendiat Friedolin Steinhardt ved Høgskolen i Innlandet.

Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

Med vennlig hilsen

Friedolin Steinhardt
e-post: friedolin.steinhardt@hil.no
tlf. 94050619

For spørsmål er det også mulig å kontakte:
Anne-Stine Dolva, anne-stine.dolva@inn.no, tlf 61288024
eller
Reidun Jahnsen, reija@ous-hf.no, tlf 23026986

### Samtykke til deltagelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

Navn: _____

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(dato, signering deltager) (dato, signering barn/unge)

## B Questionnaires

### B1 Group interviews – children

**Spørreskjema «BARNAS II»-prosjekt – barn**

Dette spørreskjemaet skal hjelpe meg til å finne ut hvem som var med i intervjuet. Skjemaene vil oppbevares innelåst i et skap ingen andre enn jeg får lese svarene. Hvis du trenger litt hjelp til å svare på skjemaet kan du sikkert spørre mamma, pappa, eller enn annen voksen om å hjelpe deg.

| Nr. | Spørsmål | Svar |
|---|---|---|
| 1 | Kjønn | ☐ gutt ☐ jente |
| 2 | Hvor gammel er du? | ___ år |
| 3 | Hvor bor du? | ☐ by ☐ landsby |
| 4 | Hvem bor du sammen med? | ☐ sammen med mamma og pappa<br>☐ delt hos mamma og pappa<br>☐ hos mamma<br>☐ hos pappa<br>☐ andre personer:_____ |
| 5 | Har du søsken? | ☐ ja, hvor mange: _____<br>☐ nei |
| 6 | Bruker du hjelpe-midler til forflytning? | ☐ nei<br>☐ man. rullestol ☐ elektr. rullestol ☐ tracks/raptor<br>☐ rullator ☐ stokk/krykker ☐ ortoser<br>☐ andre: _____ |
| 7 | Bruker hjelpemidler til kommunikasjon? | ☐ nei<br>☐ tegn til tale<br>☐ ASK (Alternativ og supplerende kommunikasjon)<br>☐ andre: _____ |
| 8 | Bruker du andre hjelpemidler? | ☐ nei<br>☐ ja:_____ |

## B2 Group interviews – parents

**Spørreskjema «BARNAS II»-prosjekt – Foreldre/foresatte**

I dette spørreskjemaet ber vi om bakgrunnsinformasjon om familien til barna som deltar i forskningsprosjektet «BARNAS II». Alle informasjon blir anonymisert og behandlet konfidensielt. Det vil ta ca.10 minutter å svare på skjemaet. På noen spørsmål skriver du inn et svar og på andre krysser du av på det alternativet som passer best. Takk for at du deltar i studien.

| Nr. | Spørsmål | Svar | | | | |
|---|---|---|---|---|---|---|
| 1 | **Mors oppvekstland** | ☐ Norge | ☐ Annet: _____ | | | |
| | **Fars oppvekstland** | ☐ Norge | ☐ Annet: _____ | | | |
| 2 | **Barnets boforhold** *(Hvem bor barnet mest/likt mye sammen med?)* | ☐ mor og far<br>☐ mor<br>☐ far | ☐ mor og ektefelle/samboer<br>☐ far og ektefelle/samboer<br>☐ andre 1: _____<br>☐ andre 2: _____ | | | |
| 3 | **Utdanning til omsorgs-personen(e) som barnet bor mest/like mye sammen med** *(høyeste fullførte utdanning)* | | mor | far | andre 1 | andre 2 |
| | | Grunnskole | ☐ | ☐ | ☐ | ☐ |
| | | Videregående Skole | ☐ | ☐ | ☐ | ☐ |
| | | Høgskole / universitet | ☐ | ☐ | ☐ | ☐ |
| | | Annen | ☐ | ☐ | ☐ | ☐ |
| 4 | **Tilknytning til arbeidslivet til omsorgspersonen(e) som barnet bor mest/like mye sammen med** *(nåværende arbeids-tilknytning)* | | mor | far | andre 1 | andre 2 |
| | | Arbeider mer enn heltid | ☐ | ☐ | ☐ | ☐ |
| | | Arbeider heltid | ☐ | ☐ | ☐ | ☐ |
| | | Arbeider deltid (50% eller mer) | ☐ | ☐ | ☐ | ☐ |
| | | Arbeider deltid (under 50%) | ☐ | ☐ | ☐ | ☐ |
| | | Er ikke i arbeid | ☐ | ☐ | ☐ | ☐ |
| 5 | **Dersom omsorgs-personen(e) som barnet bor mest/like mye sammen med ikke arbeider, skyldes det…** *(sett kryss for det som er aktuelt* | | mor | far | andre 1 | andre 2 |
| | | Arbeidsledig | ☐ | ☐ | ☐ | ☐ |
| | | Trygd | ☐ | ☐ | ☐ | ☐ |
| | | Utdanning | ☐ | ☐ | ☐ | ☐ |
| | | Ønsker å være hjemme med barn | ☐ | ☐ | ☐ | ☐ |
| | | Barnets funksjonsvansker / sykdom | ☐ | ☐ | ☐ | ☐ |
| | | Egen sykdom | ☐ | ☐ | ☐ | ☐ |
| | | Annet: _____ | ☐ | ☐ | ☐ | ☐ |

| | | |
|---|---|---|
| 6 | **Oppleves familiens økonomi som et problem?** | ☐ nei ☐ ja, på hvilken måte: _____ _____ _____ _____ _____ |
| 7 | **Oppleves familiens bolig som et problem (som størrelse, utforming)?** | ☐ nei ☐ ja, på hvilken måte: _____ _____ _____ _____ _____ |
| Nå følger en del spørsmål om barnet som du er sammen med her på oppholdet. | | |
| 8 | **Hvor gammel er barnet?** | _____år |
| 9 | **Hva slags funksjons-hemming har dit barn?** | ☐ fysisk ☐ utviklingshemming ☐ sammensatt ☐ annet:_____ |
| 10 | **Går barnet i barnehage?** | ☐ nei ☐ ja, _____ antall dager i uka |
| 11 | **Har barnet søsken / stesøsken?** | ☐ nei ☐ ja, antall _____ alder _____, _____, _____, _____, _____, _____ år |
| 12 | **Bruker barnet hjelpe-midler for forflytning?** | ☐ nei ☐ ja, _____ _____ _____ |
| 13 | **Bruker barnet andre hjelpemidler (som høre-apparat, kommunikasjons-hjelpemiddel)?** | ☐ nei ☐ ja, _____ _____ _____ |
| 14 | **Har barnet hjemmeboende søsken / stesøsken som får ekstra tiltak (som medisinske, spesial-pedagogiske)?** | ☐ nei ☐ ja |

## B3 Group interviews – healthcare professionals

### Spørreskjema «BARNAS II»-prosjekt – Fagpersoner

Dette spørreskjemaet gir bakgrunnsinformasjon om deltagerne i gruppe-intervjue. Det er viktig å kunne si hva slags personer har deltatt i studien, for å forsvare resultatene og konklusjoner. Alle informasjoner blir anonymisert og behandlet konfidensielt. Det vil ta ca.5 minutter å svare på skjemaet. På noen spørsmål skal du skrive inn svar og på andre skal du krysse av.

| Nr. | Spørsmål | Svar |
|---|---|---|
| 1 | kjønn | ☐ mann ☐ kvinne |
| 2 | alder | ___ år |
| 3 | arbeidsted | ☐ BHSS ☐ annet sted (f.eks. lokal skole, fysio-terapipraksis,... ): _____ |
| 4 | arbeidsbeskrivelse | ☐ fysioterapeut ☐ idrettspedagog ☐ ergoterapeut<br>☐ teamassistent ☐ lærer ☐ lege<br>☐ aktivitetsleder fritid ☐ annet:_____ |
| 5 | utdanningsnivå | ☐ videregående ☐ yrkesutdannelse ☐ Bachelor<br>☐ Master ☐ Doktorgrad ☐ annet:___år |
| 6 | Erfaring i arbeid med barn/unge med funksjons-hemming | ___ år |

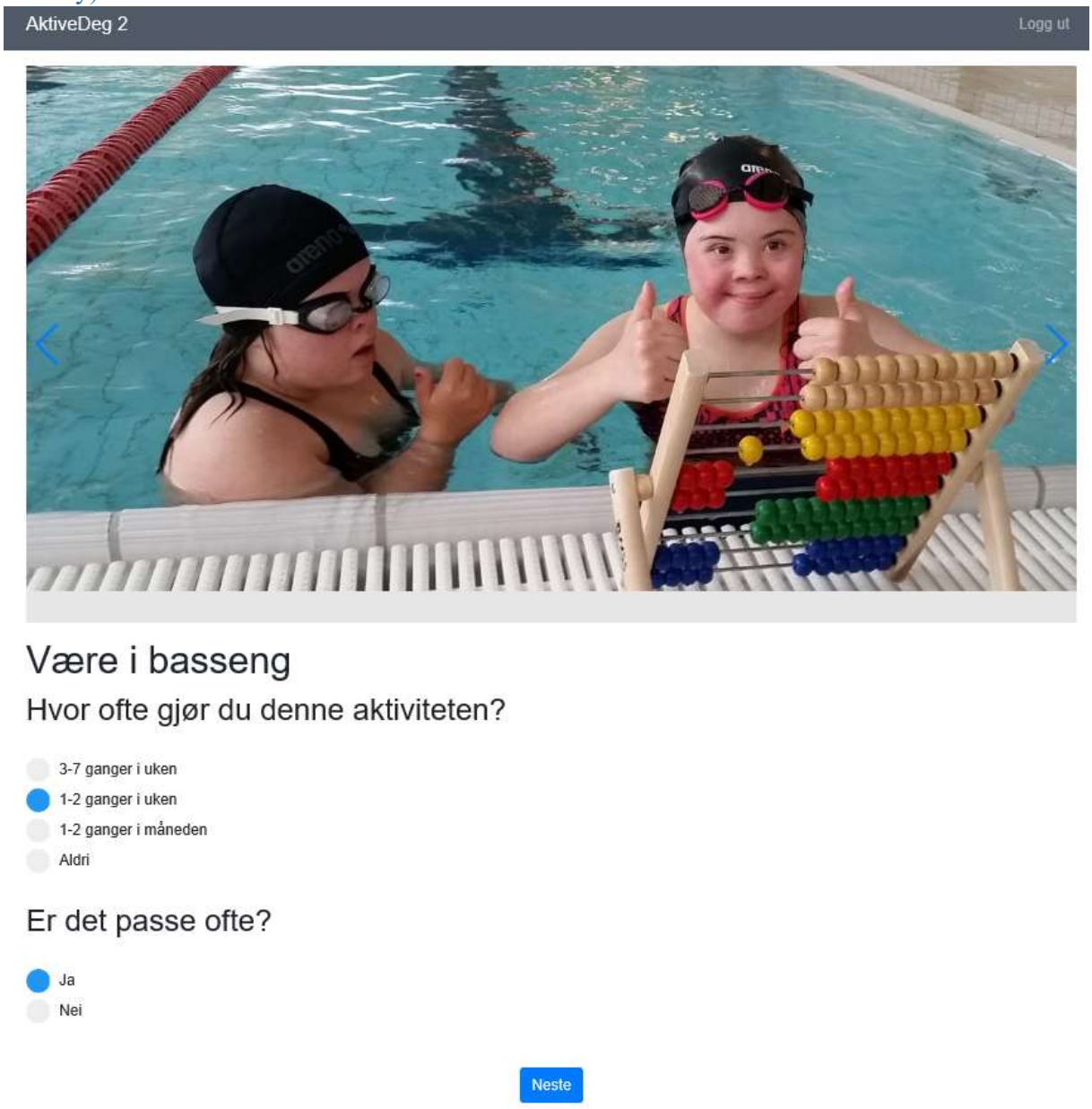
## B4 ActiveYou II – printed version for cognitive interviews

**AktiveDeg 2/ActiveYou 2**

| | |
|---|---|
| Hvor ofte har du gjort denne aktiviteten i løpet av de siste 3 månedene? | *Kryss av ett svaralternativ:*<br>☐ 3-7 ganger i uken<br>☐ 1-2 ganger i uken<br>☐ 1-2 ganger i måneden<br>☐ Sjeldnere enn hver måned<br>☐ Aldri |
| Er du fornøyd med det? | ☐ *Ja*<br>☐ *Nei* |
| Hvem har du gjort denne aktiviteten sammen med? | *Mulig å krysse av flere alternativer:*<br>☐ Alene<br>☐ Med familie (foreldre, søsken)<br>☐ Med andre slektninger (besteforeldre, tante, fetter…)<br>☐ Idrettslag, kulturskole, ungdoms-klubb…<br>☐ Selvorganisert med venner<br>☐ Med assistent, støttekontakt,… |
| Er du fornøyd med det? | ☐ Ja<br>☐ Nei |
| Aktiviteten er viktig for meg. |  |
| Det er morsomt å drive med aktivitet |  |
| Jeg klarer å gjøre aktiviteten sånn som jeg ønsker |  |
| Dette gjør det lettere for meg å delta. | *Mulig å krysse av flere alternativer:*<br>☐ Noen forteller meg hvor jeg kan delta<br>☐ Aktiviteten finnes i nærheten<br>☐ Det er gratis å delta<br>☐ Delta sammen med familien<br>☐ Delta sammen med venner |

| | |
|---|---|
| | ☐ Mamma, pappa, eller søsken følger meg<br>☐ Har med en assistent eller støttekontakt<br>☐ Aktivitetslederen tilpasser aktiviteten<br>☐ Har ikke vondt<br>☐ Har riktig utstyr |
| Dette gjør det vanskelig for meg å delta. | *Mulig å krysse av flere alternativer:*<br>☐ Vet ikke om hvor det finnes muligheter til å delta<br>☐ Aktiviteten finnes ikke der jeg bor<br>☐ Det er for lang vei<br>☐ Tidspunktet passer ikke<br>☐ Det er for dyrt<br>☐ Ingen kan følge meg<br>☐ De andre er ikke hyggelige mot meg<br>☐ Aktivitetslederen tar ikke hensyn til meg<br>☐ Blir for sliten<br>☐ Får vondt<br>☐ Mangler riktig utstyr |

## B5 ActiveYou II – digital questionnaire at the end of the Ph.D. thesis (exemplary for pool activity)



AktiveDeg 2 Logg ut

# Være i basseng

## Hvem gjør du aktiviteten sammen med?

*Mulig å velge flere alternativer*

- [ ] Alene
- [x] Med familie
- [ ] Med assistent, støttekontakt, ...
- [ ] Med andre voksne
- [ ] Idrettslag, kulturskole, ungdoms-klubb
- [ ] Med venner
- [ ] Sammen med andre barn på skolen

## Liker du det som det er?

- (•) Ja
- ( ) Nei

Forrige Neste

AktiveDeg 2 Logg ut

## Være i basseng

Hvor godt synes du at du utfører aktiviteten?

Forrige Neste

AktiveDeg 2 Logg ut

## Være i basseng

Det er morsomt å drive med denne aktiviteten

Forrige Neste

AktiveDeg 2 Logg ut

# Være i basseng

## Dette gjør det lettere for meg å delta

*Mulig å velge flere alternativer*

- [x] Kan delta sammen med familien
- [ ] Kan delta sammen med venner
- [x] Mamma, pappa eller søsken følger meg
- [ ] Jeg har assistent eller støttekontakt
- [ ] Jeg har det utstyret jeg trenger
- [ ] Aktiviteten finnes der jeg bor
- [ ] Det er gratis å delta
- [ ] De voksne som er der hjelper meg

Forrige Neste

AktiveDeg 2 Logg ut

# Være i basseng

## Dette gjør det vanskelig for meg å delta

*Mulig å velge flere alternativer*

- [x] Har ikke det utstyret jeg trenger
- [ ] Aktiviteten finnes ikke der jeg bor
- [ ] Tidspunktet passer ikke
- [ ] Det er for dyrt
- [ ] Ingen kan følge meg
- [ ] De andre er ikke hyggelige mot meg
- [ ] De voksne som er der hjelper meg ikke
- [ ] Jeg er for sliten
- [x] Jeg har vondt
- [ ] Føler meg utrygg
- [ ] Det finnes ingenting som gjør det vanskelig for meg å delta

Forrige Neste aktivitet

## PhD Dissertations in Child and Youth Participation and Competence Development (BUK)
## Ph.D.-avhandlinger i barn og unges deltakelse og kompetanseutvikling (BUK)

**No. 21** **Ingrid Bårdsdatter Bakke:** No culture for career? Conceptualisations of career as a cultural phenomenon and as experienced by tenth graders and career counsellors in Norway.

**No. 22** **Lena Catherine Westby:** Sårbare barnefamiliers erfaringer fra møter med norsk barnevern - en narrativ studie

**No. 23** **Hanne Fehn Dahle:** Butikk eller pedagogikk? En studie av store private barnehagekjeder i Norge

**No. 24** **Frode Restad:** Curriculum Making for Social Learning. Exploring Policy and Practice in Norwegian Lower Secondary Education.

**No. 25** **Ragnhild Holmen Bjørnsen:** A privileged childhood? Autobiographies of growing up in the Norwegian Foreign Service.

**No. 26** **Friedolin Steinhardt:** 'How can I participate' –Development of ActiveYou II. Development of a new web-based, self-reported instrument to measure participation in physical leisure activities for children and youth with disabilities.

Inland Norway
University of
Applied Sciences

Increasing participation has become one of the main goals and outcomes of rehabilitationinterventions for children and youth with disabilities. This is based on the knowledge about the positive effects on the physical, social and emotional development children and youth of participation in leisure activities. However, valid instruments to assess the individual's participation patterns in leisure activities and factors that might facilitate or hinder this participation aren't available for the Norwegian setting thus far.
This thesis contributes to the development-process of a new instrument – ActiveYou II - which aims to cover the need for such an instrument. Several research-methods during this process are used. To enhance the understanding of two important subdimensions of participation – involvement and engagement – a structured literature search, using the scoping review method, was carried out. In group interviews with children, parents and healthcare professionals, facilitators and barriers for the participation in leisure activities in the Norwegian setting were investigated. Finally, cognitive interviews were used to test a first version of the instrument for Item Quality and Applicability.