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Designing game-inspired mobile applications to promote physical activity for individuals with intellectual disabilities

Master's thesis in Informatics
Supervisor: Maria Letizia Jaccheri, Javier Gomez Escribano, Juan Carlos Torrado Vidal
May 2019

Master's thesis

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Trondheim, May 31, 2019

Ingrid Evensen, Jens Brandsgård Omfjord

Summary and Conclusions

Motivation: An estimated 1% of the world population are living with intellectual disabilities. Studies have indicated that there are very low levels of physical activity in this part of the population. Physical activity is proven to help reduce the rate of serious diseases.

Objective: This thesis investigates the possibility of creating mobile applications to promote physical activity for people with intellectual disabilities. It will also look into the evaluation of such applications with the user group.

Method: The research strategy employed in this thesis is design and creation. A literature review, a focus group, interviews, and observations are used as data generation methods.

Findings: A low fidelity prototype developed using guidelines based on the literature review and resources on intellectual disabilities was evaluated in a focus group. The results from the focus group were used in creating revised guidelines, a revised prototype, and an adapted test framework for testing the application.

Contribution: The contribution to knowledge are guidelines for development and testing mobile applications aiming to promote physical activity in individuals with intellectual disabilities. As a result of the work towards obtaining project approval from The Norwegian Center for Research Data, the contribution also includes guidelines for obtaining ethical research approval in IT projects involving individuals with intellectual disabilities. In addition to this, an academic paper has been submitted to the I3E conference.

Limitations: The main limitation is missing user testing, after the two recruited test groups, unfortunately, backed out. Thus, the revised guidelines and prototype was not evaluated by the intended users.

Conclusions: Applications intended for use by people with intellectual disabilities requires special considerations during design and development. The guidelines presented in this thesis will help developers customize their applications for use by individuals with intellectual disabilities.

Key words: *Intellectual Disabilities, Physical Activity, e-Health, Gamification, Mobile Applications*

Sammendrag og konklusjon

Motivasjon: Av verdens befolkning er det estimert at 1% lever med psykisk utviklingshemming. Studier viser at mengden fysisk aktivitet er veldig lav hos denne gruppen. Fysisk aktivitet er bevist å redusere risikoen for å utvikle alvorlige sykdomer.

Forskningsmål: Denne masteroppgaven utforsker mulighetene for å utvikle mobilapplikasjoner for å promotere fysisk aktivitet hos mennesker med psykiske utviklingshemninger. Oppgaven vil også finne alternativer for å teste slike applikasjoner med brukergruppen.

Metode: Forskningsmetoden som har blitt brukt er design og utvikling. Et litteraturstudie, en fokusgruppe, intervjuer og observasjoner ble brukt til datainnsamling.

Resultater: En første prototype ble utviklet ved bruk av rettningslinjene som er basert på litteraturstudiet og ble evaluert i en fokusgruppe. Resultatene fra fokusgruppen ble brukt til å lage oppdaterte rettningslinjer, en oppdatert prototype og et tilpasset testrammeverk for testing av prototypen.

Bidrag: Denne masteroppgavens bidrag til feltet er retningslinjer for utvikling og testing av mobilapplikasjoner med mål om å oppfordre til mer fysisk aktivitet hos mennesker med psykisk utviklnigshemming. Som et resultat av arbeidet for å få prosjektet godkjent av Norsk senter for forskningsdata inneholder bidraget også retningslinjer for å oppnå etisk godkjenning i IT prosjekter som involverer mennesker med psykisk utviklingshemming. I tillegg har en akademisk artikkel blitt innsendt til konferansen I3E.

Begrensninger: Manglende brukertesting etter de to planlagte testgruppene dessverre trakk seg, betyr at evaluering mangler fra den tiltenkte brukergruppen.

Konklusjon: Mobilapplikasjoner utviklet for å brukes av mennesker med psykisk utviklingshemming krever egne hensyn når det gjelder design og utvikling. Retningslinjene presentert i denne oppgavnen vil hjelpe utviklere å tilpasse deres applikasjoner for brukere med psykisk utviklingshemming.

Nøkkelord: *Psykisk utviklingshemming, Fysisk aktivititet, e-Helse, Gamification, Mobilapplikasjoner*

Acronyms

AAC Augmented Assistive Communication

CD Cognitive Disability

Exergame Exercise Game

ID Intellectual Disability

LD Learning Disability

NSD Norwegian Centre for Research Data

NTNU Norges Teknisk- Naturvitenskapelige Universitet
(Norwegian University of Science and Technology)

PA Physical Activity

REK Regional Committees for Medical and Health Research Ethics

SG Serious Games

SUS System Usability Scale

W3C World Wide Web Consortium

WAI Web Accessibility Initiative

WHO World Health Organization

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Chapter 1

Introduction

1.1 Motivation

An estimated 1% of the world population are living with intellectual disabilities Pivalizza et al. (2018). Among the group of people diagnosed with intellectual disabilities, studies have pointed towards very low levels of physical activity Hilgenkamp et al. (2012); Temple (2007, 2009) with only a small minority meeting the levels of physical activity recommended by both global and national health organizations World Health Organization; Helsedirektoratet.

According to the World Health Organization, all adults between the age of 18-64 years old have the same recommendation for a minimal level of physical activity per week. These requirements are *at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week*. Evidence shows that meeting these requirements can result in an overall lower rate of serious diseases such as coronary heart disease, high blood pressure and stroke World Health Organization.

Physical activity will also help reduce the risk of becoming overweight and the increased health risks associated with being overweight or obese. WHO (2009) shows that physical inactivity and obesity are among the leading risks for mortality in the world today.

A study from 2010, Haveman et al. (2010) reviewing health-related literature on intellectual disabilities and aging, indicate an increasing focus on health risk factors. These factors include being overweight and obese, and is linked to the onset of other diseases and severe health conditions. It is concluded that a healthier lifestyle and more exercise was an excellent way to improve the overall health of this specific group of adults.

1.2 Project description

The goal of this master thesis has been to identify ways gamified mobile applications might increase physical activity amongst people with intellectual disabilities and use these to develop guidelines for such applications. These guidelines are based on the factors that facilitate physical activity in individuals with intellectual disabilities. The facilitators and barriers were identified during the literature review that was conducted as the initial part of the research.

To gain insight into how well the user group received the prototype application, and how it encourages an increased level of physical activity, a user test was planned. To make this user test fit the intended user group and to provide the most valuable data possible, an adapted test framework was developed. This framework was a result of the literature review, resources on intellectual disabilities as well as a focus group.

A focus group was held, where the topics discussed included the initial design guidelines developed from the literature review. The prototype that was developed using the initial guidelines was also discussed. From this focus group, a set of revised design guidelines was developed. The revised guidelines inspired the development of a revised prototype, which was to be the application tested with recruited participants from the user group.

The user test would require the collection and storage of personal data; therefore, the ethical side of the research needed to be addressed. A research notification was submitted to and approved by NSD (Norwegian Centre for Research Data).

The project is a part of a larger research project by the name of *Effect of physical activity*

with e-health support in individuals with intellectual disabilities. A randomized controlled study. The project is a cooperation between The Norwegian Arctic University (UiT), The University Hospital of North Norway (UNN) and The Norwegian University of Science and Technology (NTNU).

1.3 Research questions

The goal of the research is to develop guidelines and to evaluate a prototype application based on these guidelines. Consequently, the research questions are:

RQ1 How can we create mobile applications to promote physical activity for people with intellectual disabilities?

RQ2 How can we evaluate these applications?

RQ1 is the primary research question of the thesis and will focus on the creation of mobile applications for the user group. RQ2 is a secondary research question and will support the primary research question by researching ways to evaluate mobile applications tailored to individuals with intellectual disabilities, and especially to promote physical activity.

In addition, an academic paper has been submitted to the DTIS workshop of the I3E conference. This paper can be found in the appendix A.

1.4 Thesis structure

This thesis is structured into nine chapters. Chapter 1 is the introduction, which includes a project description, motivation as well as research objectives and research questions. Chapter 2 gives an overview of the research strategy and methods used in this project. Chapter 3 contains the literature review, including state of the art and practice. The findings from the literature review are used in chapter 4, design and development of a mobile application prototype. Chapter 5 describes the process of obtaining research approval

from *The Norwegian Center for Research Data*. The findings are presented in chapter 6, this includes the guidelines resulting from the application development, as well as the results of the focus group and observation. Chapter 7 is where the contributions from this project are presented, before being discussed in chapter 8, which also includes a section on limitations and critique. Finally, the project conclusion can be found in chapter 9, where the authors also propose possible future work.

Chapter 2

Proposed methodology

The proposed methodology employed in this thesis is based around the design and creation strategy (see section 2.1) Oates (2006). Figure 2.1 shows the data generation methods used, which include a literature review (see section 2.2), interviews (see section 2.3), a focus group(see section 2.4) and observations (see section 2.5).

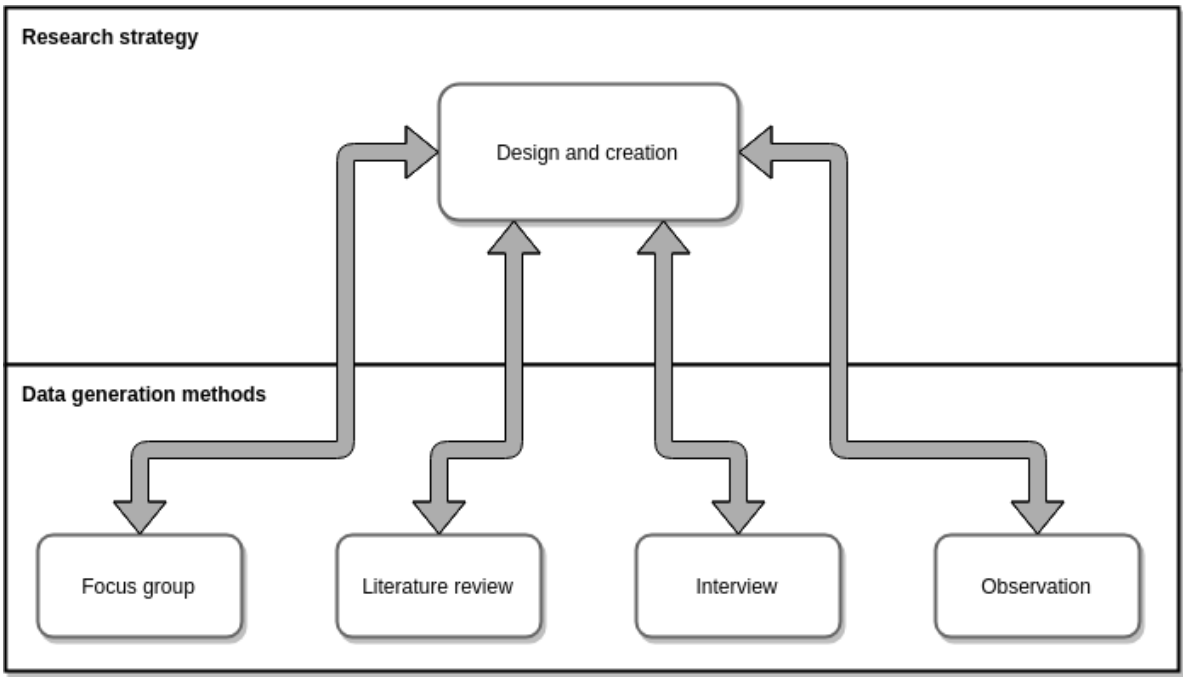


Figure 2.1: Research strategy and data generation methods

Figure 2.2 shows the flow of the project that involves the following steps:

1. First, a literature review is conducted to gain theoretical insight into the fields explored in this thesis. This review provides the basis for the initial guidelines for designing game inspired applications for people with intellectual disabilities.
2. The first set of design guidelines are used to develop a low fidelity prototype.
3. The low fidelity prototype is used to apply for research approval from The Norwegian Centre for Research Data (NSD)
4. The approved NSD application results in guidelines on applying for research approval in projects utilizing technology for people with intellectual disabilities.
5. The low fidelity prototype is presented and discussed in a focus group.
6. The results from the literature review and the feedback from the focus group make up the foundation for the revised development guidelines.
7. The results from the literature review and focus group are used to develop an adapted test framework.
8. The revised design guidelines are used to develop a revised prototype.
9. The adapted test framework is used while conducting a user test, that includes observations followed by an interview, with recruited participants from the user group
10. The results from the user test are combined with the literature review and the focus group to produce a final set of design guidelines.
11. The final design guidelines are the basis for the final prototype.

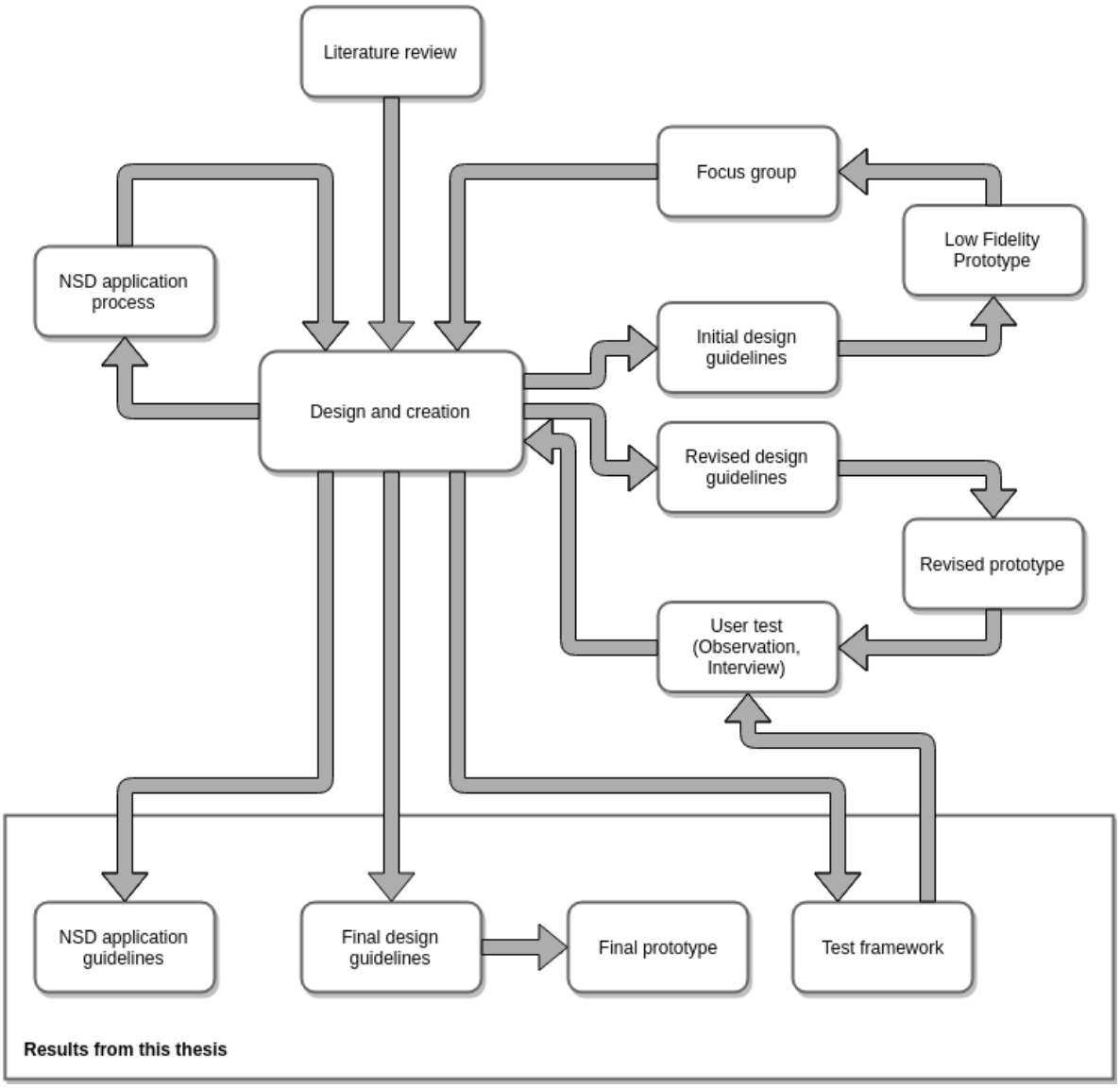


Figure 2.2: Research and development flow

2.1 Design and Creation

The research strategy design and creation places focus on the development of new IT products Oates (2006). The research output of design and creation can be different IT products, including:

- **Constructs** is the vocabulary of the domain.
- **Models** are the relations between different constructs
- **Methods** are sets of steps used to perform specific tasks
- **Instantiations** are the combination of the constructs, models, and methods, working together in a system

When using design and creation as a research strategy, the contribution to knowledge can consist of one of the above mentioned IT products or a combination of them all. Using this approach, a complete IT system using new knowledge, or existing knowledge in a new way, can itself be a contribution to knowledge March and Smith (1995), Oates (2006).

2.2 Literature Review

The literature review is often the initial effort towards awareness of existing work on the domain. The review will contribute towards placing the work in the context of existing research and help when analyzing the future results.

A literature review can be used both to discover research topics and ideas and to support the new research being an important topic, building on existing research effort in the field and that the new research is a contribution by creating new knowledge Oates (2006).

According to Oates (2006), a successful literature review consists of searching, obtaining, assessing, and reading documents before doing an evaluation and writing a critical review.

Search engines like IEEE Xplore IEEE (2018), ScienceDirect Elsevier (2018), and Google Scholar Google (2018) have been used to perform the search and obtain the documents.

Using different combinations of specific *search words* , relevant documents got selected by identifying keywords and concepts in the abstract and conclusion and further using a combination of *inclusion criteria* listed in table 3.1, to identify the most relevant. Lastly, if any of the papers do not follow the *quality assesments* defined in table 3.1, they will be ignored in the literature review.

2.3 Interview

An interview is a good way of obtaining detailed information on a subject. Different types of interviews provide different types of information, suited to different studies Oates (2006).

Structured interviews are useful for obtaining multiple answers to the same questions from a larger group of people Oates (2006).

Semi-structured interviews let the interviewee speak more freely on a subject, but is still limited to the themes that are predefined for the interview, possibly raising different perspectives on a topic then what the interviewer expected. This approach might also make it easier for the interviewee to share their knowledge Oates (2006).

Unstructured interviews are limited to the predefined topics of the interview, which allows the interviewee to explore the subject more freely Oates (2006).

2.4 Focus group

Focus groups are carefully planned discussions, designed to obtain the perceptions of the group members on a defined area of interest Kontio et al. (2004). To have an effective focus group and to avoid fragmentation in the group, the ideal size is 5-10 people. Using this group size means all participants can have their views and opinions heard, and the group can still be large enough to accommodate a diversity of perceptions Krueger and Casey (2000).

The goal of a focus group in product or program development is to gain valuable insight from the intended users of the product at the early stages where it is still possible to

make potential changes and adjustments to the product.

2.5 Observation

Observations, in a computing research perspective, can provide data on how participants interact with computer systems. It can also be used to analyze how they perform certain tasks, highlighting how that task can be improved by a computer system. This information can be used at different stages of development to ensure that the system fits the needs of the user in the best possible way Oates (2006).

While observing participants, researchers can figure out what participants actually do, rather than what they report that they did when asked about the same action in an interview. There is widespread use of observations as a data generation method amongst researchers in HCI (Human-Computer Interaction).

One of the shortcomings of observations as a data generation method is the fact that the researcher is the sensor gathering data, which raises the question of a possible bias in the reported observations. There are ways to help encourage the validity of the data. For example, it is recommended to use quotations from the observations, rather than just summarizing what was said. Another approach is to triangulate the data or methods, by either observing multiple participants performing the same action or by combining the observations with another data generation method. Using an interview to triangulate the results will give the participant a chance to confirm your observations Oates (2006).

Chapter 3

Literature Review

3.1 Search Strategy

Data collection for the literature review was done through an internet keyword search through relevant databases, such as IEEE Xplore IEEE (2018), ScienceDirect Elsevier (2018), and Google Scholar Google (2018). Keywords used in the searches are the following, or a combination of them; *intellectual disabilities, health, physical activity/ies, intervention(s), e-Health, m-Health, mobile, applications, technology, serious game(s), exergame(s), gamification, design, alternative communication, activity tracking, Fitbit, sensors*

The resulting articles and papers from the search were narrowed down by reviewing the title and abstract of the papers to identify relevance for this project. Inclusion criteria and quality assessment metrics are listed below in table 3.1. The search resulted in 35 academic sources (See appendix B.1 for a summary table) further discussed in section 3.2 State of the art and 3.3 State of the practice.

Inclusion Criteria	**Quality Assessment**
English or Norwegian language	University publisher
Content of the abstract and/or results	Academic publisher
The paper is related to one of the research questions	Conference paper (preferably annual and long-running conference)
The paper gives a unique view of at least one research question	Part of an established journal (preferably with a high issue number)
Peer-reviewed	
Not older than 2005	

Table 3.1: Inclusion criteria and quality assessment

3.2 State of the art

3.2.1 Health challenges in individuals with intellectual disabilities related to physical activity

Several studies have shown evidence that a sedentary or inactive lifestyle is more prevalent in people with intellectual disabilities Bossink et al. (2017); Hilgenkamp et al. (2012); Temple et al. (2006); Temple (2009); Haveman et al. (2011).

Different studies investigating physical activity in people with intellectual disabilities have found results varying from 14%(Peterson et al. (2008)) to 33%(Temple et al. (2006)) of participants reaching recommended levels of physical activity. A study from 2016 reviewed 14 studies, and found that only 9% of adults with intellectual disabilities reach the daily recommended levels of physical activity set by the World Health Organization Dairo et al. (2016). The varying findings can be a result of different methodologies, sample sizes and the studies using different guidelines on recommended physical activity for health benefits Dairo et al. (2016).

Doing physical activity and reaching the daily recommended physical activity levels set by the World Health Organization can reduce the risk of becoming overweight or obese, and the increased health risks that bring. A review of weight loss interventions for adults with intellectual disabilities from 2007 Hamilton et al. (2007) states that rates of obesity

are generally higher for people with intellectual disabilities than the general population [1]. These rates also seem to be the case in adolescents with intellectual disabilities, as shown in the study by Queralt et al. (2016).

A sedentary lifestyle, physical inactivity, and obesity can correlate to life-threatening diseases such as and cardiovascular disease certain types of cancer, type 2 diabetes as well as increased risk of physical injury from falling and increased risk of depression World Health Organization; WHO (2009). The World Health Organization estimates between 20-30% of these life-threatening diseases come from or are related to physical inactivity.

When trying to understand why this health challenge is more prevalent in this population with intellectual disabilities, it is essential to look at how they perceive healthy and unhealthy behavior as well as identifying facilitators and barriers for participating in physical activity, and other activities for health benefits such as healthy eating habits.

Identifying, planning, and following a healthy lifestyle can be more challenging for people with intellectual disabilities than the general population. A study by Kuijken et al. (2015) found that the concepts of what was healthy or unhealthy could be very abstract and challenging for a person with intellectual disabilities. One reason for this is the amount of contradictory information available, that can confuse what to believe. For anyone looking to find information on health, there is a lot to find, especially as the internet and other social media have made access to information so much more available. Contributing to this confusion is that the concept of healthy/unhealthy is often seen to be very binary for many. Either something is seen as always healthy or always unhealthy, and moderation is a concept that is abstract and hard to understand.

A cross-sectional study from 2012 by Hilgenkamp et al. (2012) show that lack of physical ability such as limited mobility and walking speed, can be a contributing factor to why many people with intellectual disabilities are more sedentary than the general population.

[1] The obesity rates for men with IDs: 11.7-26.5%
Rates for men in the general population 3.9–23.1%
The obesity rates for women with IDs: 23.1-58.5%
Rates for women in the general population: 3.6–28%

Another study reviewing health-care data on 1,4 million adults[2] found that adults with intellectual disabilities have a higher likelihood of more than just one health condition and a significantly higher rate of physical conditions Cooper et al. (2015).

3.2.2 Barriers and facilitators for physical activity in individuals with intellectual disabilities

There are several studies that have tried to identify facilitators and barriers for physical activities in this group of people Temple (2007, 2009); Bodde and Seo (2009); Badia et al. (2011); Kuijken et al. (2015). Among the findings were a preference for sedentary activities, the importance of positive role models, and support from authority figures. There was also a link between motivation for physical activity when it is associated with socializing and friendship Kuijken et al. (2015); Temple (2009).

Two papers by Temple (2007, 2009) identified *barriers that hindered physical activity in people with intellectual disabilities* and *factors [that] were associated with high levels of physical activity in people with intellectual disabilities.* In these two papers, a preference for inactive recreational activities among participants, such as watching TV and movies. The paper identifying barriers showed that the higher the number of perceived barriers for physical activity reported by a participant, the more likely they were to have a sedentary lifestyle. Sedentary activities were also seen as having few barriers, which made them preferred by many participants.

The other study focused on identifying the factors associated with high levels of activity in people with intellectual disabilities. Individuals with higher levels of physical activity were more likely to have a positive influence from caregivers, parents, and other authority figures. The motivation for activity could also stem from doing something rewarding like participating in the Special Olympics or socializing. Individuals having an active job, hobby or chore are also more likely to be more physically active.

[2] 8014 (0.56%) of them had intellectual disabilities

The study by Bossink et al. (2017) aimed to identify facilitators and barriers and show a lot of the same results as the studies by Temple (2007, 2009). The study found the most frequently reported barriers being health issues, financial issues, and lack of support as well as transportation. Among the facilitators were social interaction and doing activities with others, doing fun activities, and working towards a reward.

The review by Bodde and Seo (2009) analyzed seven papers and found that the main barriers for physical activity include transportation issues, financial cost, lack of facilities, and lack of support from caregivers or authority figures. The need for positive influence is also supported by Temple (2009), where results show that individuals with intellectual disabilities who were physically active often had positive influence from these authority figures. Social support is listed as one of the key success factors for increasing physical activity in adults with intellectual disabilities by Melville et al. (2015). Badia et al. (2011) also concludes with a supportive environment is a big facilitator towards physical activity, and that having somebody teach them or show them the way led to those participants being the most physically active.

Overall, the studies investigating facilitators and barriers for physical activity in this group of people often have similar findings. A summary of the most commonly identified facilitators/motivation and barriers for physical activity from the different papers and articles are listed below in table 3.2, in no order of preference.

Facilitators	**Barriers**
Social interaction and friendship	Lack of facilities for physical activities
Working towards a goal	Physical inability
Feeling healthy	Cost of physical activities
Having work that requires PA	Enjoying unhealthy food and activities
Having fun	Lack of support and guidance from key support persons

Table 3.2: Facilitators and barriers for PA in people with IDs

3.2.3 Physical activity interventions for individuals with intellectual disabilities

Studies show that physical activity interventions and getting more active have a positive health effect on people with intellectual disabilities. Oviedo et al. (2014) tested the effects of a combined physical activity program using both aerobic, strength, and balance training to investigate the effects on endurance, strength, and balance. The results of the study saw positive changes in all metrics compared to the control group.

Shin and Park (2012) analyzed the effect of exercise programs for individuals with intellectual disabilities by comparing 14 studies using different exercise programs for health interventions. The study concluded that the effect of exercise programs on people with intellectual disabilities was positive and gave a few indications on what duration and frequency of exercise is the most effective. The results showed that short-duration exercise is more effective than long-duration, with the most effective duration being 31-60 minutes.

A trial study by Melville et al. (2015) tested a behavioral change program designed to increase walking and daily step counts on people with intellectual disabilities. The outcome of the study was no change in overall step count and showed that sedentary participants did not increase their daily step count to gain potential health benefits.

So while the studies by Oviedo et al. (2014) and Shin and Park (2012) shows positive outcomes where the participants are doing the activities, the study by Melville et al. (2015) show that we cannot assume that an intervention program that has proven efficacy when tested on the general population, can undoubtedly be adopted by people with intellectual disabilities.

Generally, there exists fewer studies and research on people with intellectual disabilities than people without intellectual disabilities Hamilton et al. (2007). The lower number of studies also reflects that people with intellectual disabilities only represent around 1% of the population Pivalizza et al. (2018).

In addition to it being fewer studies in general, the review from Hamilton et al. (2007)

reviewed research articles and papers and found that several intervention studies had weaknesses when it comes to evaluation and validity. These shortcomings could be because of the short time-frame of the study, not having a control group and not doing follow up controls of the results to see if the intervention caused permanent weight loss. It also suggests that for this group of people, physical activity interventions can be more relevant for promoting weight control than significant weight loss.

The study by Hilgenkamp et al. (2012) also illustrates why researching physical activity in this group of people can be a challenge. In the study, from a potential of 1050 candidates with intellectual disabilities, only 257 participants count towards the results. Other candidates were disqualified due to lacking physical ability, having too slow walking speed, non-cooperation, or lack of understanding.

3.2.4 Technology and Intellectual Disability

At the projects start, the authors had never developed an application with the specific user group in mind and therefore needed more knowledge regarding the user group and technology.

Intellectual disability is a diagnosis where every individual face different challenges, but according to the *International Statistical Classification of Diseases and Related Health Problems 10th edition (ICD-10) World Health Organization (2016)* intellectual disabilities is an incomplete development of the mind, leading to impairment of skills that describe overall intelligence such as language, motor, social and cognitive skills.

The article Lorentzen (2008) defines intellectual disabilities according to the ICD-10 classification World Health Organization (2016) and is describing how to set the diagnosis of intellectual disabilities in Norway. The article also describes how intellectual disabilities means a lack or deficit of abilities and adaptability in the following areas; motor skills, day to day activities, expressive and receptive language, reading/writing and social skills like building and maintaining relations, interactions with other people.

The Diagnostic and Statistical Manual of Mental Disorders (5th edition) American Psychiatric Association (2013) describes different levels of intellectual disabilities and the impact on the conceptual, social, and practical domain. Understanding written communication and abstract ideas can be difficult in varying degrees for people with intellectual disabilities, meaning abstract thinking and executive function is impaired.

A paper by Miesenberger and Petz (2014) says that people with cognitive disabilities can face problems with "standard information on the web and applications" because of difficulties with; memory/problem solving (conceptualizing, planning, sequencing, reasoning, and judging) and attention (reading, literacy, verbal and visual comprehension).

Generally, technology can be a more significant challenge to someone with intellectual disabilities than someone without disabilities. As several studies show, special considerations must be made when creating applications for people with disabilities Antener et al. (2014); George et al. (2014); Wiemeyer et al. (2015); Edler and Rath (2014).

The study by George et al. (2014) found no established methodology to verify the usefulness and quality of an information system for people with an intellectual and cognitive disability. There was expressed a need for such a tool. Antener et al. (2014) supports this, and show the need for clear guidelines in developing digital media for people with intellectual disabilities.

George et al. (2014) also makes a point of the difficulty of evaluating technology or systems created for people with IDs because of the varying degree of knowledge of technology and information systems as well as that it is hard to use standardized methods to get feedback from this user group. George et al. (2014)

World Wide Web Consortium (W3C) is an international community that started in 1993, where member organizations, staff, and the general public develop internet standards W3C (2018a). W3C promotes people with disabilities in accessing, using, and interacting with the web through the Web Accessibility Initiative (WAI) Laabidi et al. (2014). On the WAI website W3C (2018b), a section on accessibility fundamentals gave some examples of potential barriers for people with cognitive disabilities that should be taken into account, like complexity and relying too much on text. However, the guidelines gave, in

general, broad advice and suggestions, not necessarily focusing on the specific challenges someone with intellectual disabilities might have. This is supported in the study by Edler and Rath (2014) who discussed where user-centric design is necessary and if to involve the user group in development. Previous development for people with disabilities has been through using general accessibility guidelines like W3C/WCAG W3C (2018b). Edler and Rath (2014) argues that the measures taken in these guidelines do not solve the key challenges for people with disabilities that might not be because of a technical nature. Antener et al. (2014) agrees in her paper that organizations wanting to create accessible digital media for people with intellectual disabilities miss guidelines or instructions and that WCAG 2.0 does not have enough information specifically meant for this user group. Hersh (2014) also claim these existing guidelines are mainly focused around needs of people with mobility and sensory impairments, and although they are useful as a checklist, they do not provide coverage of all the different challenges that might impact a person with intellectual disabilities.

People with disabilities face different challenges like navigation, pacing, and exclusively text-based interfaces. This is supported by Miesenberger and Petz (2014), Antener et al. (2014) and Wiemeyer et al. (2015) who also argues the special needs for people with developmental/intellectual disabilities differ from the ones covered by general accessibility.

Even though many studies claim there is a need for adaptations and specialized applications, Edler and Rath (2014) mentions that the younger generations are getting more familiar with digital tools and media, as they have used them growing up. This raises the question that using non-specialized applications could give a sense of independence and inclusion for people with intellectual disabilities.

3.3 State of the practice

3.3.1 Existing commercial alternatives

Among commercial alternatives; Argus, Pedometer, Apple Health and Google Fit are popular applications to track and increase daily physical activity Apple (2019); Google (2019b). These applications use the built-in sensors of the device such as pedometer, and GPS-tracking to measure step count, daily activity and speed Azumio (2019); ITO Technologies (2019); Apple (2019); Google (2019a). These applications let users monitor their health, personalize goals, set milestones, and join in on challenges that are meant to help motivate towards more physical activity and the following health benefits.

Gamification is defined in the Cambridge dictionary as the *practice of making activities more like games in order to make them more interesting or enjoyable* Cambridge Dictionary (2018). Game mechanics often found in e-Health applications include achievement systems, social interaction, and feedback messages Wang and Sun (2011).

The amount of gamification vary in the different applications, but there is a gamification element in that there is progress bars, achievements, badges, and trophies, and there is the possibility to compete with friends, or engage with the community also using the same application, to motivate and compete together. In addition to this, there exist methods that are known to affect behavior regarding health. A systematic review from 2018 reviewed different techniques for behavior change in mobile applications for physical activity Kuru (2018). Among the most common ones were; providing feedback on performance, prompting goal settings, instructions, planning social support, social comparison, social support, and providing rewards.

Although many application need only a smartphone to do the tracking, some applications exist as an interface to wearable devices. Examples of these applications are Garmin connect, Fitbit and PolarFlow, and they all rely on information synced from a wristband or watch. The wearable bands and watches range from simple, just a pedometer to the more advanced with optical heart rate monitoring, GPS and accelerometer.

Several studies from 2015 looking into accuracy and preciseness of wearable devices and smartphone technology when it comes to step count and activity tracking, find the technology to be sufficiently effective to be used in estimating physical activity Cadmus-Bertram et al. (2015); Diaz et al. (2015); Case et al. (2015); El-Amrawy and Nounou (2015). The study Case et al. (2015) found that data collected from smartphones had a lower error of the actual step count than wearable devices where one of the tested devices had an observed step count 20% smaller than the real number. Diaz et al. (2015) used FitBit to track step count and energy expenditure during walking and running, and found that it may be *an accurate, reliable, and efficient tool for physicians to track the adoption/maintenance of physical activity programs and support their patient's attempt at an active lifestyle.*

Chapter 4

Design and Development

This chapter describes the design and development of the mobile application prototype. That includes a description of early concepts, reasoning behind the choice of application type, reward system, and communications. All the decisions were made as a result of the findings in the literature review, national resources on intellectual disabilities[1], feedback from supervisors and the projects network.

4.1 Early concepts

4.1.1 Concept 1: Application to track activity with TV-control unit

This concept was an idea presented as part of the project description as a possible way to use technology to increase physical activity in people with intellectual disabilities. As sedentary behavior is enjoyed and perceived as activities with low barriers in the user group, the idea was to take advantage of this in developing an application to motivate for physical activity. The application would use all physical activity and convert that to a virtual currency, which could be used to buy time watching TV or films. The concept included the use of a separate TV-control unit that would only allow for the TV to be switched

[1]These resources include the web pages of The Norwegian Directorate of Health, The National Institute on Intellectual Disability and Community (NAKU) and national service for special needs education (STATPED)

on if the user had enough of this virtual currency.

Taking the ability to do a preferred activity away from the users, and by doing so, punishing them for not being physically active enough, did not seem like the right way to motivate the user group. According to findings in the literature review, studies identifying motivation factors for physical activity emphasized the importance of positive reinforcement Kuijken et al. (2015); Bossink et al. (2017). Although working towards a goal and achievement was described as a motivating factor in Temple (2009), this should not be done by taking away something they already have access to and be used as a punishment.

4.1.2 Concept 2: Exergame

The use of serious games and exergames are a growing trend, which is gaining more legitimacy as a tool to solve health-related challenges Wilkinson (2016); Crookall (2010). Exergame is a term derived from the words "Exercise" and "Gaming," and although there are different definitions to be found in different studies and projects, most of them define exergames as video games that require physical activity to play the game. Oh and Yang (2010)

The idea was to develop an application that would allow the user to interact with the game through either a treadmill or exercise bicycle.

The authors decided early against an exergame, which requires more user involvement and being able to follow along on the screen for longer periods. Also, both cost and lack of facilities are perceived barriers to physical activity. Creating the exergame would depend on additional hardware like an exercise bicycle, treadmill, or wearables.

4.1.3 Concept 3: Gamified application to increase daily physical activity (Selected for development)

This idea is to take inspiration from the existing applications that focus on reaching simple everyday goals regarding physical activity like Google Fit, Apple Health, and Fitbit. These applications have the functionality but are not designed or developed with the projects

specific user group in mind. As many of these commercial apps have a lot of information, fast pace and rely heavily on the user understanding abstract concepts such as time, statistics, charts, and progress bars. The studies from Antener et al. (2014); George et al. (2014); Wiemeyer et al. (2015); Edler and Rath (2014), states that this user group needs adaption or specially designed application to meet their needs regarding functionality, pacing, design, and communication.

This concept was chosen for further development because it appeared to have the least potential barriers for the users with the only requirements being the ability to walk unassisted as well as owning and being able to operate a smartphone.

4.2 Design

Developing applications for people with disabilities need special considerations that are not necessarily present when designing for the general population. This section describes the decisions made regarding the application development supported by the literature review, descriptions, and diagnosis of intellectual disabilities as well as feedback from the projects supervisors and network.

4.2.1 Application type

The application will not require any use of wearable technology. As the literature review helped uncover many barriers towards physical activity, an advanced application where a user needs to ensure the connection between a mobile phone and a wearable device was not ideal. This way, the only thing required is a mobile phone.

Since the application is meant to track activity and movement data wherever and whenever a user wants, it will not be required of the user to engage with the application at all times. It will have to be possible to put the phone away, partly because the application is meant to be used outdoors where users must be alert to their surroundings.

The application developed is game-inspired in the sense that it uses elements known

from gamification, such as rewards, social interaction, and feedback to keep the user involved in the application.

4.2.2 Reward system

Reward systems in gaming can be seen as player motivators or ways to ease disappointment Wang and Sun (2011). From mapping the known facilitators and barriers for physical activity (see section 3.2), the facilitators can be used towards creating a reward system to be used in the game, while at the same time trying to overcome potential barriers.

In a list compiled by Wang and Sun (2011), different reward systems in games are identified. They suggest eight different categories, where one or more is suitable for any game. Based on the findings during the literature review, two types might fit our application well — these were achievement systems and feedback messages. Using rewards and feedback is also known methods to affect behavior change regarding health Kuru (2018). In the achievement-based systems, users earn prizes, medals or badges. The feedback-based systems provide the user with positive feedback for smaller accomplishments during the gameplay itself. These systems might work well for the application prototype as it allows providing feedback and encourages users to keep going a little longer while using the application, as well as rewarding them with different badges and medals symbolizing their achievement or progress.

These are the mechanisms to be implemented in the application to reward and notify users;

1. Rewarding situations where the participants are active together with others. Studies found that friendship and socializing was a facilitator for physical activity in the user group.

2. Rewards are to be presented through getting badges, medals, or achievements.

3. Notifications to users that they are doing good. Positive reinforcement and a form of support

4.2.3 Communication

When designing technology for people with intellectual disabilities, it is important to focus on how to communicate and present information to the user.

Although intellectual disability is very individual and everyone has their challenges, there are still some general suggestions learned from the literature review that will be the focus. Having a slower pace of presenting information and limiting the amount of information on each page or view as visual comprehension can be limited Miesenberger and Petz (2014). Abstractions such as showing progress through lines, bars, and numbers can be difficult for someone with intellectual disabilities. The same applies to connecting an avatar or symbol to a real person, as understanding abstract ideas can be difficult American Psychiatric Association (2013). Relying only on text as a way of communicating is also a challenge as language is a challenge many people with intellectual disabilities face, including reading, literacy, and understanding written information World Health Organization (2016); Miesenberger and Petz (2014).

As written communication and abstract ideas can be difficult in varying degrees for people with intellectual disabilities, one should try to use more than one way of communicating a message. This means to not just present information by text, but accompanying it with icons or symbols to help the recipient understand the intent and meaning of the message.

Using various methods or tools to help communication in addition to text falls under the term AAC - Augmentative and Alternative Communication[2] Communication Matters (ISAAC UK). Several symbol sets have been designed, especially with AAC in mind; there is everything from sign language, photographs, complex computer systems, and graphics such as icons and symbols. While researching communication using icons or symbols, no national standard or recommended best practice was identified by the authors. It would be preferable to use a system that is commonly used and established in Norway so that the user might have encountered or used before. Although no standard was found, ac-

[2] In Norwegian - ASK (Alternativ og supplerende kommunikasjon)

cording to isaac[3] Norge, the most used AAC symbol systems in Norway are photographs, pictograms, Picture Communication Symbols (PCS), Widgit Literacy Symbols (WLS), Symbolstix and Bliss. isaac Norge (2019) A description of the most common AAC symbol systems in Norway can be found in appendix B.2.
Through the network of the project the authors were able to use the PCS symbols from the symbol set provided by Tobii Dynavox (see appendix B.2).
This list sums up the special considerations regarding communication that will be used in the development of the prototype;

1. Do not use numbers alone as an indication of progress
2. Represent real people with real pictures, not avatars or icons
3. Limit the use of text-only to present information, supplement with symbols

4.3 Prototypes

The prototypes developed as a part of the research in this thesis was based around an iterative process. The result of this process is two prototypes that have been based on the initial- and revised design guidelines. This section aims to present both prototypes.

The overall flow of both prototypes is the same and is explained in subsection 4.3.3. The images used are developed, and made available to the authors, by Tobii Dynavox Tobii Dynavox, a company specialized in AAC.

4.3.1 Low Fidelity Prototype

The low fidelity prototype was developed from the first set of guidelines, which are based on the findings from the literature review. The low fidelity prototype was a non-functional prototype, meaning that it consisted of still screenshots as opposed to fully functional

[3]International Society for Augmentative and Alternative Communication

code. It was decided to use this approach as it allows for more rapid prototyping, allowing time for multiple iterations of the prototype.

The prototyping software Figma was used to link the still screenshots together, to provide a more lifelike experience when interacting with the prototype. This allows the developer to use the prototype on a phone like any other application.

4.3.2 Revised Prototype

The revised prototype was developed from the revised guidelines. These guidelines are an iteration of the initial guidelines and have been updated to incorporate the findings from the focus group. The revised prototype has been developed as both a non-functional prototype like the low fidelity prototype and as a functional app available for Android phones.

The technology selected for the development of the functional prototype was React Native. The choice landed on React Native based on the recommendation of a supervisor, as it was claimed to support rapid prototyping in a good way. A closer look into academic literature also confirmed this statement Axelsson and Carlström (2016); Furuskog and Wemyss (2016).

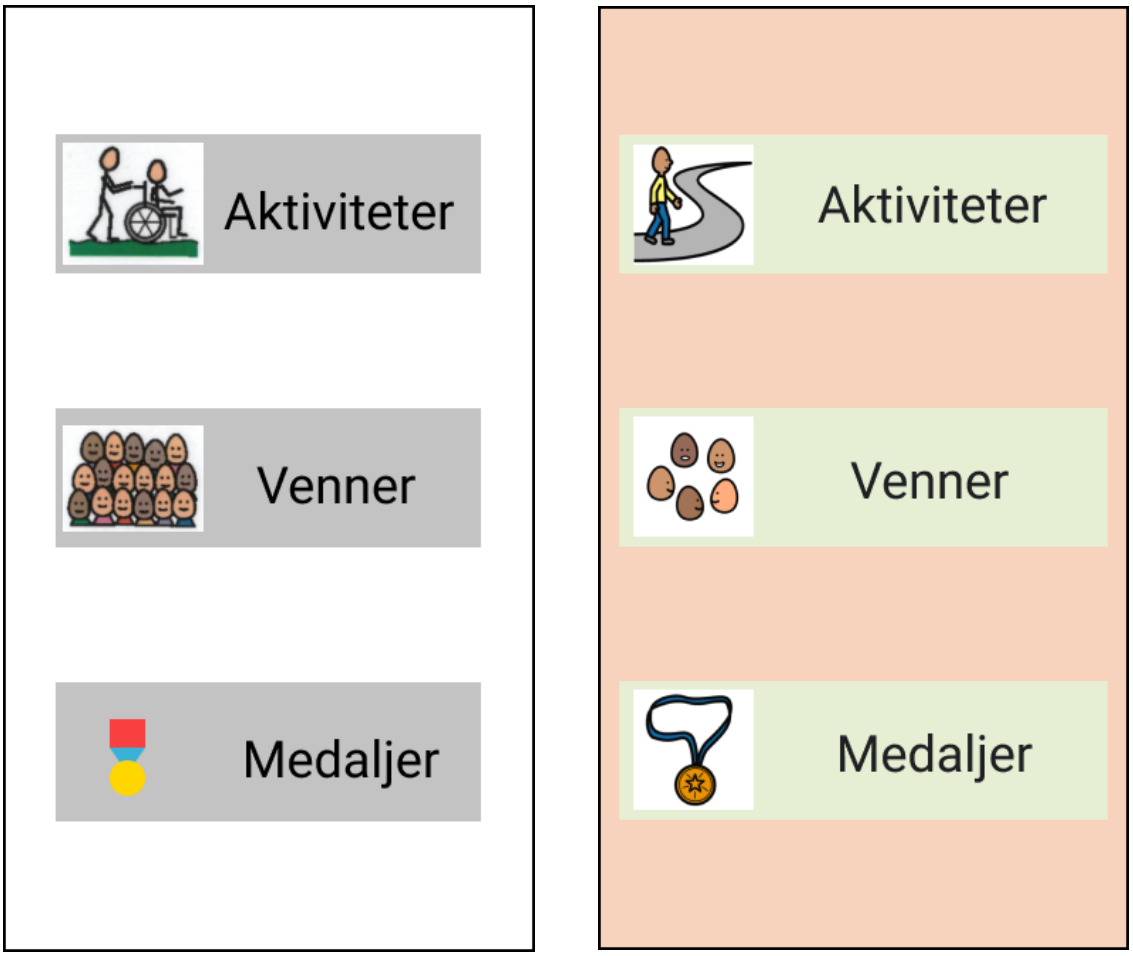
The following is a list of the main changes in the revised prototype:

- The flower bouquet was removed, and a single flower with animation was added in its place.
- A progress bar has been added to display the time elapsed in multiple ways
- The color scheme has been changed. The contrast between the background and text is WCAG approved.

4.3.3 Prototype flow

Figure 4.1 shows the main screen of the low fidelity and revised prototype. From here, users can navigate to the activities screen, the friend screen, or the achievement screen.

Following the initial guidelines, all the information is displayed in multiple ways. In this case, the different selections are presented with both an image and corresponding text.



(a) Low fidelity prototype (b) Revised prototype

Figure 4.1: Prototype main screen

The activity flow, shown in figure 4.2 and 4.3, gives the user the choice between different activity types. The activities included in the example flow include walking, dancing, and bicycling. The flower(s) symbolize the daily activity progress. As the user performs different activities, the flower blooms until the daily goal is met, at which point the flower is in full bloom. Using a flower as an indicator on daily progress might provide more life-like feedback on progress, then numbers can. Once an activity is completed or canceled, the user is returned to the activity screen.

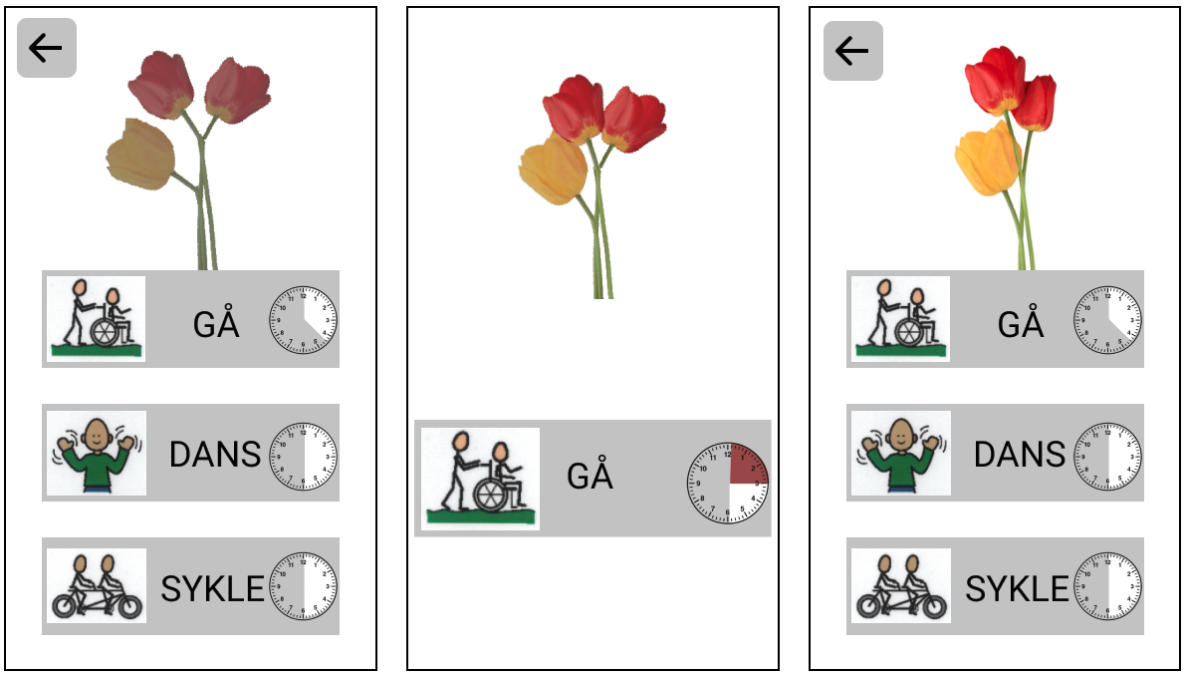


Figure 4.2: Low fidelity prototype activity flow

The friends screen, shown in figure 4.4, provide an overview of the users friends. Here you are presented with a list consisting of all the users friends. It is possible to further navigate to the friends profile to view their medals and badges. The profile images are intended as an illustration of how the profile cards could look. These would be updated with pictures of the actual users in a real-world scenario.

Figure 4.5, shows the medals, or achievements the user has gained. This is included to make the app competitive, allowing different users to compare their progress.

Figure 4.6, shows examples of notification to motivate the user to reach their daily goal.

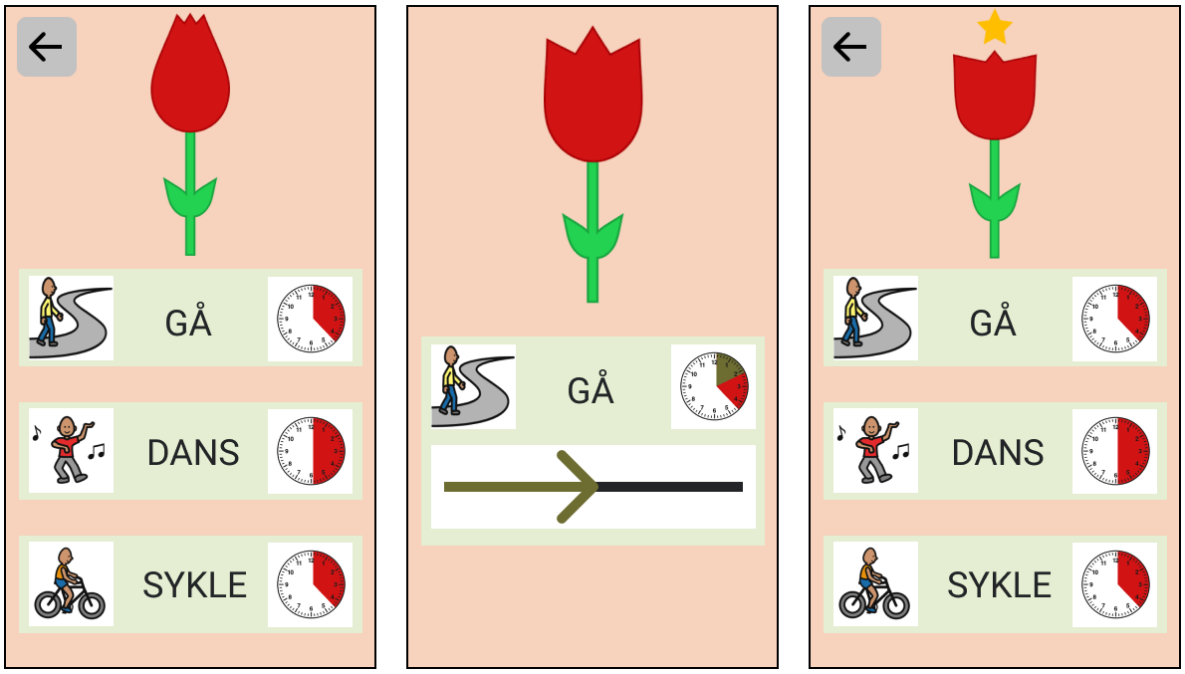
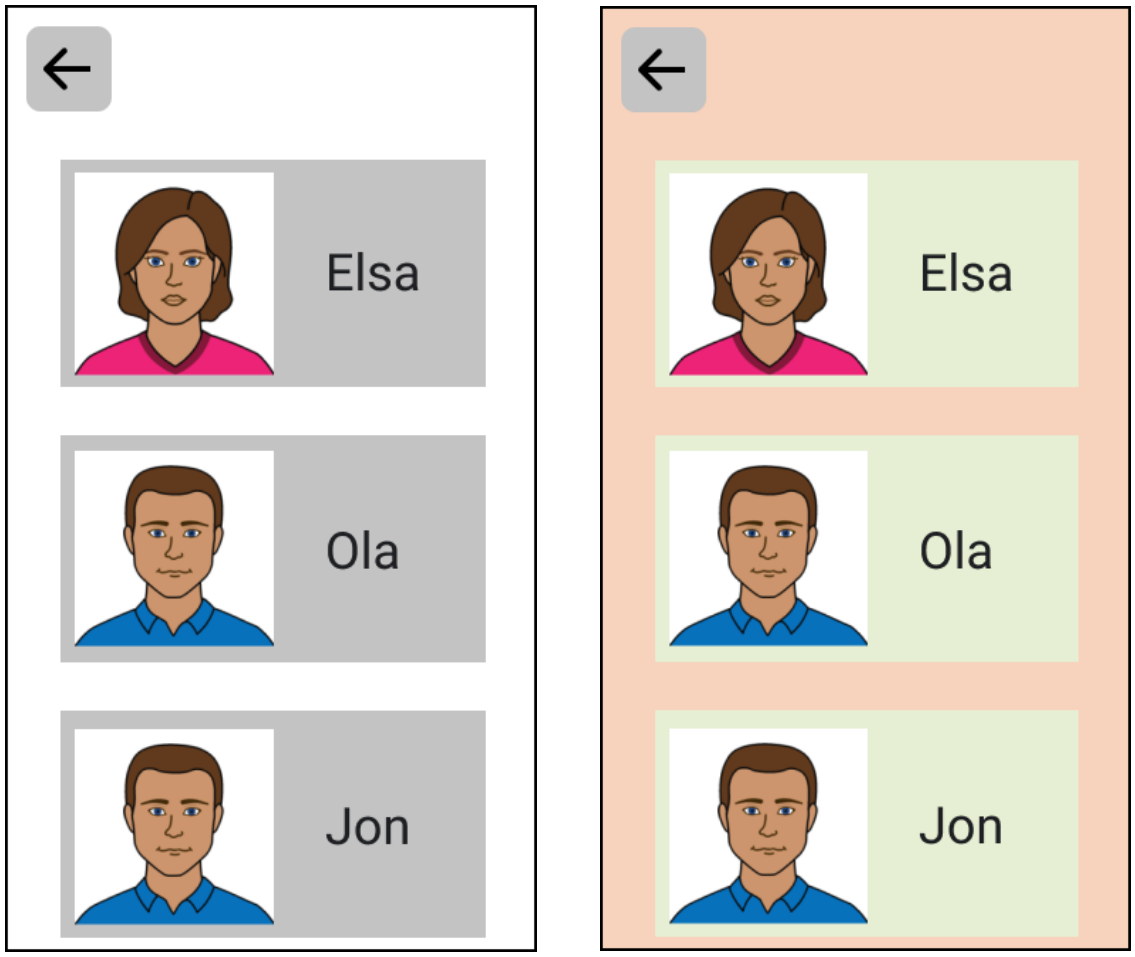


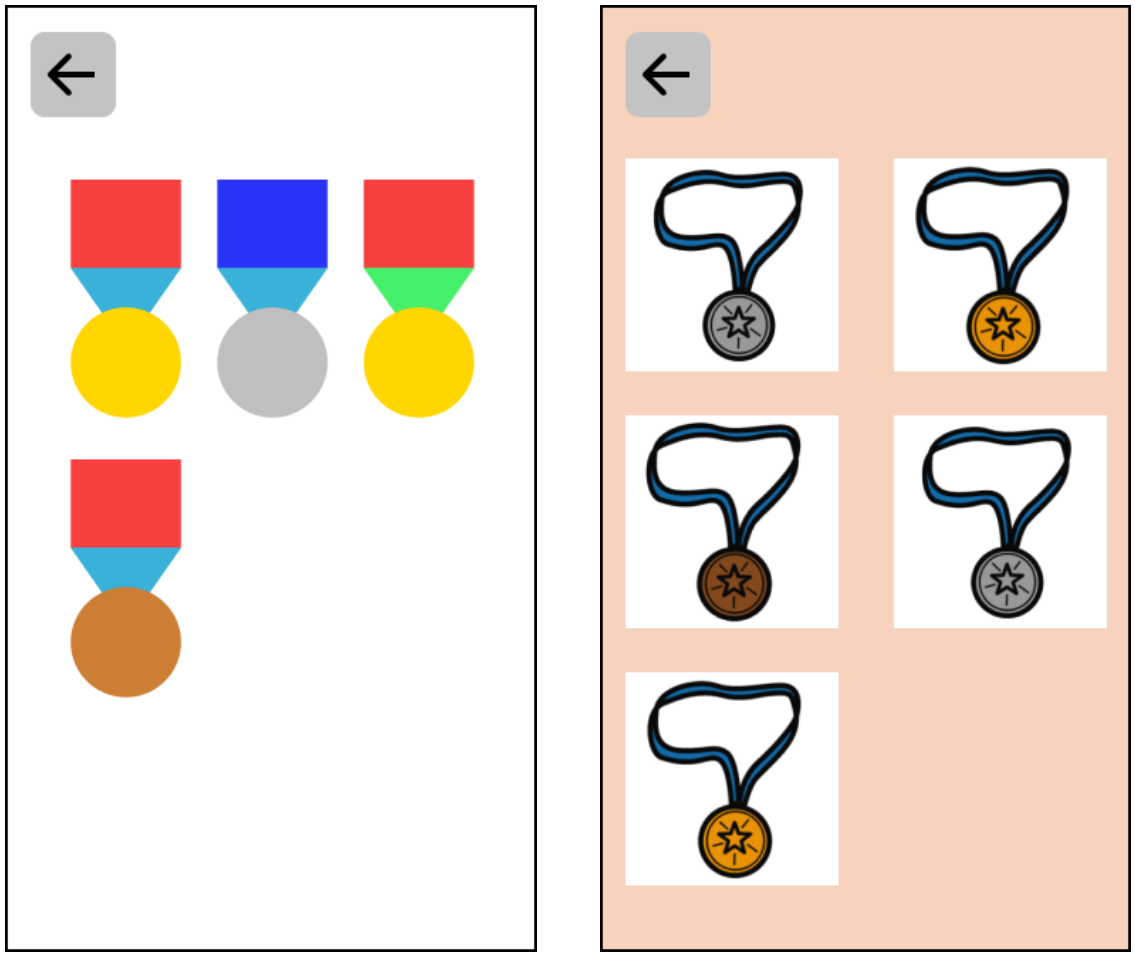
Figure 4.3: Revised prototype activity flow



(a) Low fidelity prototype

(b) Revised prototype

Figure 4.4: Prototype friends screen



(a) Low fidelity prototype

(b) Revised prototype

Figure 4.5: Prototype medals screen

(a) Notification on home screen

(b) Notification on locked screen

Figure 4.6: Prototype notification screen

Chapter 5

Ethics

In any project that requires personal data to be collected, analyzed, or stored, research ethics has to be considered, and often approved by a separate entity.

This project made the proper applications to the relevant research ethics committees. Individual consent to participate was collected and stored for all participants, including those with legal guardianship, where the participation and consent were to be approved from the participants' legal guardian. The approval granted by the NSD (Norwegian Center for Research Data) and REK (Regional Committees for Medical and Health Research Ethics) is included in the appendix C together with examples of information letters, approval form and adapted information letter.

In this thesis, the research ethics has an entire chapter devoted to itself due to the amount of work required in order to gain research approval for this project. One of the contributions of the thesis are guidelines on how to make the research approval process as easy as possible in research including people with intellectual disabilities. The guidelines are presented in section 7.3 and further discussed in section 8.3. The authors hope that it will be a tool for both current and future researchers in the field.

5.1 REK - Regional Committees for medical and health research ethics

REK provides (among other services) advance approval for medical and health research projects. This thesis is part of a larger research project; "Effect of physical activity with e-health support in individuals with intellectual disabilities" where technology is used to develop support for the promotion of physical activity in people with disabilities. Since this thesis will likely require medical and health data, the required applications were made. The application included all the sub-projects, which includes this thesis work. The REK application approval is included in the appendix C.1

5.2 NSD - Norwegian Centre for Research Data

NSD is a Norwegian national archive for research data, and includes a section for privacy and provides research approval as well as advice regarding privacy to researchers and students in around 150 collaborating institutions.

5.2.1 Obligation to notify

NSD had to be notified about the project because it would require access to, and handling of personal data. Also, institutions that have an agreement with NSD, where research will be processing personal data, should notify NSD about these projects. NTNU has such an agreement with NSD.

The requirements for not notifying a project is that the data is anonymous, and the requirements for data to be considered anonymous will not be met by this project. Even if no personal information is published, data that could identify a person will be processed and stored during the duration of the project. NSD (2019)

5.2.2 Application requirements

In the online application form, different information about the project is required. First, what kind of personal data was being collected, the different types of data, and general information about the project.

There needs to be a description of the samples[1] and how recruitment is to be done. All methods of data collection also have to be described and justified, with separate attachments required for each method of data collection. In this case, that meant an interview guide and questionnaire for each sample. Other required attachments per sample were information letters and consent forms. There is also a section for describing how personal data will be processed, who will have access, and how. The last sections cover information security, duration of the data processing, and any additional information. All the attachments used to complete the NSD approval form can be found in appendix C.2

5.2.3 Application process and challenges

A particular case for this project is the intended user group potentially lacking capacity to give legally valid consent. That lead to the need for adapted information and being able to justify processing data and potentially causing a privacy concern for this group of people.

As some of the participants in sample 1[2] might not be capable of consent that is legally valid and binding, the NSD application required a justification of the collection of personal data as *a task in the public interest*. There also needed to be descriptions of the efforts put towards minimizing the privacy concern of those not capable of giving consent.

To minimize this concern, and to sufficiently inform those incapable of consent, adapted information was provided. The adapted information was in the form of an information letter, using very simple language and short sentences, while at the same time informing about the purpose of the research, what participation would mean for the participant, what data would be collected, and that participation was voluntary and participation

[1] A sample is a group of people whose data will be processed
[2] This is the sample including people with intellectual disabilities

could be withdrawn at any time without reason.

The language used was inspired by the Norwegian version of a European standard for making information easy to understand Inclusion Europe (2019). This was done to make the information letter more accessible.

Whether or not to describe GPS/location data as *background information* or a separate set of personal data was hard to explain satisfyingly, leading to a lot of back and forth between the team and the NSD privacy advisors. This was because the authors wanted to store GPS data as part of the user testing of the application, in order to track activity progress. The privacy advisors misunderstood it as storing their *home location, i.e. where they live* which they deemed unnecessary.

Another challenge was the new regulations following the introduction of GDPR[3], which meant there needed to be special consideration to how and where data was stored. NTNU students have access to the collaboration tools through Microsoft OneDrive, where project documents and data would be stored. NSD advisors argued that Microsoft is a third party and potential threat to the participant's privacy. The NSD representative suggested the authors should obtain a legal document from Microsoft explicitly stating that data stored on NTNU OneDrive would not be shared to a third party and could be considered safe. The authors were able to argue that because NTNU hosted their own Microsoft collaboration servers, the files stored using OneDrive would be safe, and it was enough to satisfy the NSD advisor.

5.2.4 Documents

Documents describing methods used for providing participants with information and describing data collection was uploaded to the online application. These documents can be found in the appendix C.2 and include;
information letters for participants intended to test the application (see appendix C.2.1), participating support persons[4] (see appendix C.2.2) and a separate version (using adapted,

[3] General Data Protection Regulation
[4] Caregivers, parents or guardians

easy to read language) of the information letter intended for the participants with intellectual disabilities (see appendix C.2.3).
The interview guides for participants (see appendix C.2.4) and support persons (see appendix C.2.5) and questionnaire is also included (see appendix C.2.6).

5.2.5 Application timeline

The work towards applying for research approval started on December 13th, 2018, with the first submission being January 22nd. The notification approval was received on March 8th.

The following figure 5.1 shows the timeline of the application process with interactions from both NSD privacy advisers and the teams. This notification application was meant to give research approval to two separate master projects using the same intended user group.

The initial rejection was because the application did not include 'full name' in the data to be collected, but as the consent form was to require a signature, the full name was effectively being collected.

After the second submission was denied, the rejection message included many more requirements, meaning the application needed a lot more work than first anticipated. Much work was done between the second and third applications towards writing information letters and consent forms using adapted language. There also needed to be an included justification to why research would involve people who might not be able to give consent. GDPR[5] also meant the authors needed to explain and justify how and where the collected data was stored.

The application was approved on March 8th, and recruitment of participants for a test group could begin.

[5]General Data Protection Regulation

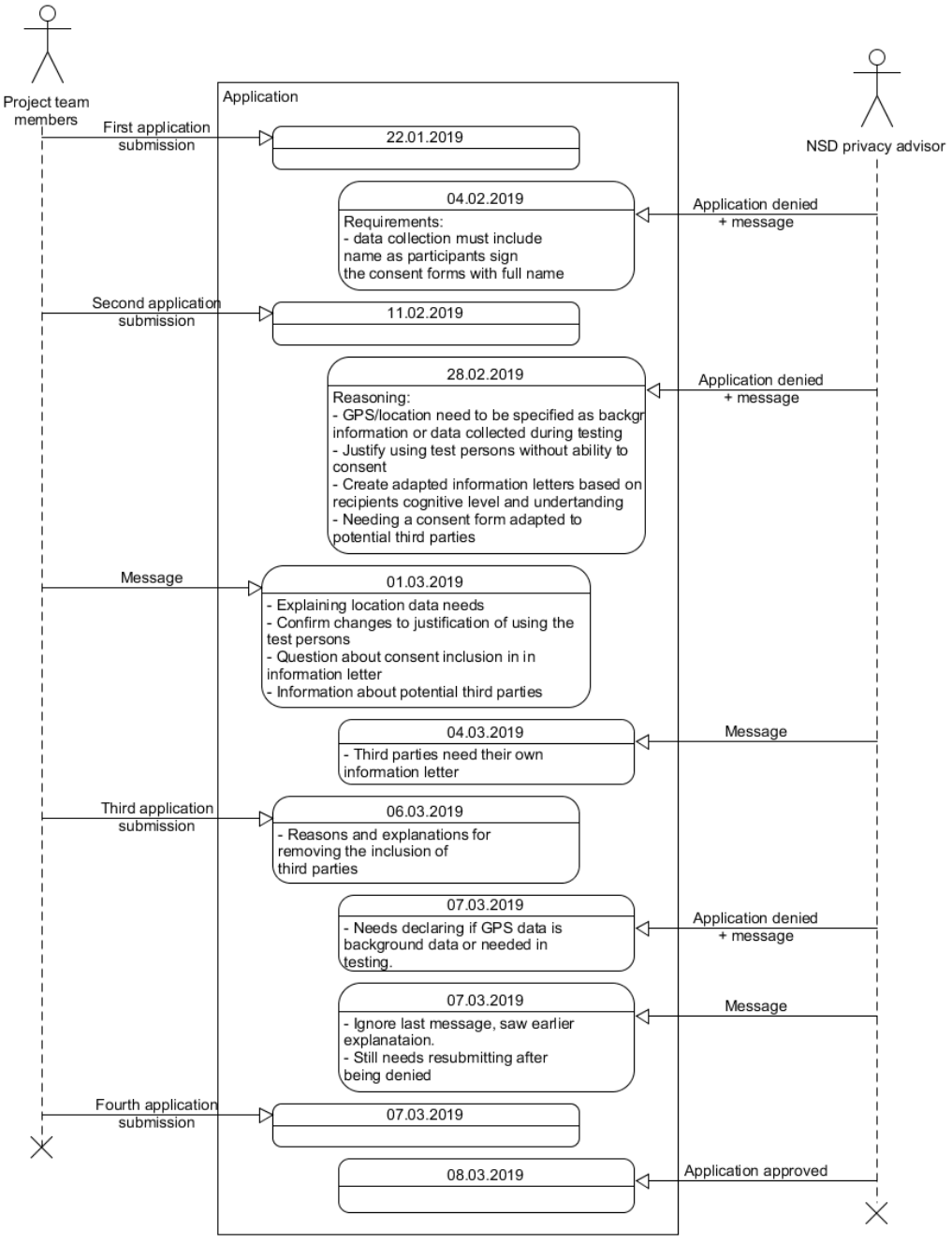


Figure 5.1: NSD Application timeline

Chapter 6

Findings

This chapter presents our findings. These include the initial application development guidelines, the findings from the focus group, and the user group observations. The revised guidelines are presented in chapter 7, as they are part of the contribution.

6.1 Initial Application Development Guidelines

6.1.1 System functionality

Guideline	**Example use**
All activity counts towards the main goal, based on WHO recommendations (The goal can be active time or steps, and should be customizable)	Have the application track activity even when the phone is locked
Additional activity can be selected by the user	The user has the ability to start a dancing activity from the activity screen
The system should encourage doing activities together with a someone (Friend, family member, care taker)	The user can view their friends achievements as well as invite them to participate in their dancing activity

There should be a reward system	The flowers blooms and the user receives a medal

Table 6.1: Initial system functionality guidelines

6.1.2 Design

Guideline	**Example use**
The user interface should focus on simplicity	The activity screen displays the necessary information in a simple way, without to many interfering visual elements
Limited use of color	The initial prototype uses a simple color scheme consisting of mostly white and grey
Use high contrast	The text used throughout the prototype follows the WCAG standards for contrast
Not making it look childish or like it was made for children	Avoid using cartoon-like avatars
Customizable interface for the individual user (showing different preferred activities)	Allowing the app of a user that cannot swim to hide swimming activities
Customizable themes	Allowing the user to choose their own font-size and color scheme

Table 6.2: Initial design guidelines

6.1.3 Communication

Guideline	Example use
Simple, non-ambiguous language	Using single words to describe the different activities
Using visual aids to support text	Using Augmented Alternative Communication images alongside text
Abstract concepts such as time and progress should be visualized by something else than a clock, numbers and progress bars	In the initial prototype, progress is displayed by a bouquet of flowers blooming

Table 6.3: Initial communication guidelines

6.2 Focus group

To get input on the proposed guidelines that would be used in the prototype, a focus group was held consisting of 4 post-doctorates working at NTNUs department of computer science with experience in application development, user experience, and design. Participants with expertise regarding the user group were one physical therapist and one occupational therapist, both currently working with people with intellectual disabilities. The participants were recruited through emails sent to appropriate educational institutions and municipal services and through the network of the project.

The focus group was organized to start with the authors giving some information about the project, the motivation behind the project as well as background information. Then there was a presentation of the research objectives and challenges before presenting the specific guidelines for the different themes of functionality, design, and communication as described in section 6.1.

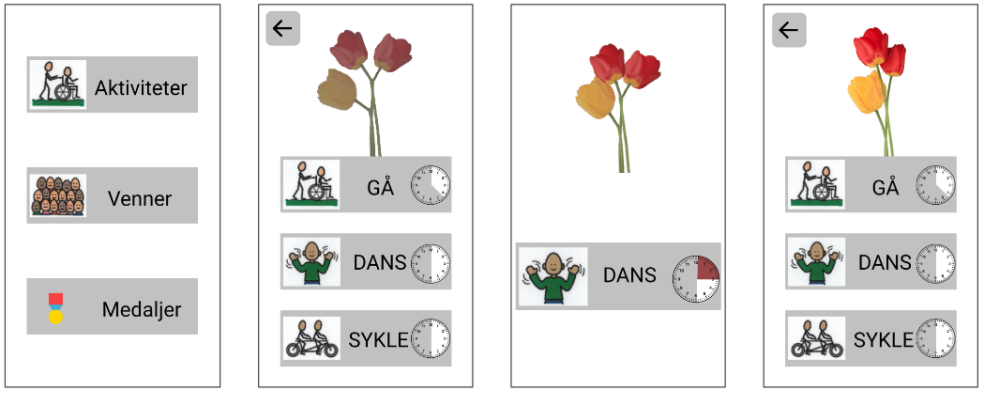


Figure 6.1: Initial prototype

The very simple illustration (Figure 6.1) showed the focus group participants the intended flow of the application where a user would chose activities, and then sets of a timed event, where activity will count towards the reward of seeing the flowers bloom.

For each of the presented guidelines, there was time for questions and a general discussion around the proposed guidelines. In addition to that, the authors had a list of questions that could be asked explicitly if not covered during the discussion;

1. Do you disagree with any of these guidelines?
2. What level of customizability should be available to the users? And what level of customizability should be available for the caregivers?
3. Is the app too “childish”?
4. How to represent the concept of time for the user group?
5. Any input on how to present progress during the day?

Starting the discussion on the suggested functionality. Basing the levels of physical activity on World Health Organization recommendations were supported by both therapists working with people with intellectual disabilities.

> "Just comment on that you based it on WHO recommendation, I think that’s very important, and to use the guidelines, what’s the facts we know about

> physical activity, because there is a lot of myths, so if you are scientists, I think that's good."

It was mentioned that levels of activity could be customized. Someone having a sedentary lifestyle could find it overwhelming and have a hard time starting with a goal of 10,000 steps per day, rather than a lower goal.

> "It's primary about health, not creating athletes"

> "And also the level required to get from here to here [Gesticulating blooming flower] should be able to be customized, but provided with some defaults to encourage an increase in daily PA [Physical activity] if you're, say, at 10% of recommended levels, maybe the first goal should be 20% instead of 100%. And then increase it up to the desired level, or beyond."

The visualization of progress was questioned by one participant

> "Why did you choose a flower?"

When the authors told it was just used as a proof of concept, one participant said

> "The flower as a symbol for progress reminds me of a system [..] based on the traffic lights, and it started being green, and when they [students] behaved badly, it's supposed to go to yellow, and then to red."

> "I don't think you should use a bouquet though."

> "Yes, I agree, a flower is better "

Since it is easy to show different states of the flower in bloom, and that having the possibility to impact that can be motivation for some people. It is about the symbolic reward and being able to make the change of states happen. As one participant describes it

> "Flower may be suitable, because if they know that the final state can be influenced, and be positive [..]. I know that in my experience you don't even need the physical reward, they want that flower to open, as much as they want that symbolic reward, that's something that can happen."

The idea of representing progress with the blooming flowers was good but should be easy to know when the goal is reached, and you are "done" for the day. As one participant asked

> "So if they reach the goal and the flower blooms, are they going to get any feedback of that?"

Backed up by another saying users could be updated on their progress;

> "[..] having notifications and prompts during the day, like you're getting close to actually getting there, then you could probably get a suggestion "do this, for this long."

And going further into the subject of notifications

> "[..] if it's getting very late in the day, maybe you can get a notification where you're missing just a few hundred steps, or if you go outside for a quick walk you will reach your goal, so hopefully there will be some notifications and communication during the day[..]"

The notifications should be relevant so that a user that is far from reaching the daily goal is prompted with a suggestion or reminder of how close they are to reach the goal. Active users should be notified that the goal is reached, but not get activity suggestions if they are done with the goals for the day.

The authors then asked the question about being able to customize (i.e., selecting what activities to choose from) the application, and one participant said

> "It could be part of the signing up process, like the caregiver can select, because the caregiver knows the users, so they know like, no swimming, so they can just choose them upfront, and that could be customizable by caregivers,

> but then also users can add or have the option to choose whether I want to do that or that"

Another participant added

> "You don't need a large list [of activities], because if they really liked 10 activities, they probably didn't need this application"

Another important point made by one of the participants regarding the actual safety of using the application

> "I think that if there's some [activities] that the individual is not capable of, or then there should be a way for those not to be options at all, [..] maybe a caretaker [choosing] would be good, as long as if I was going to give a user the app, that I forehand had the ability to remove swimming like if he didn't know how to swim"

Generally, customizability is an important feature as the user group is so diverse, and it is important to consider the safety of a user regarding what activities are shown.

Moving on to the guidelines on design and communication, the authors had the suggested guideline that the application should not be childish. The point was made that commercial applications that have a childish interface still can be popular with adults.

> "[..] I think that these people, as long as you use symbols, and it's quite clear what the symbols means, like candy crush is a good example for us grown-ups, many people played it, and that's a pretty childish thing, [..] It's more important that it's clear. And that what it is. Visual things, these people learn quickly. As long as it's clear it's not important what it is. "

The recommendation was therefore to remove focus from the application not being too childish. It is more important that it is clear and easy to use.
One of the topics most discussed was how to display time and the visual metaphors for time, first with one participant saying

> "I think its worth to spend some time thinking about the visual metaphors for time."

When another suggested just using a clock, the occupational therapist answered

> "They don't always understand the concept. You could use a line, and an arrow going up that line, it's very difficult with time, it's very abstract."

Another suggestion was from one participant experienced in the user group from working on their Ph.D.

> "One that worked was filling the screen. Like with water or color. That worked really well."

Animations and to show objects changing gradually can be effective to show the passing of time and change of states.
Another subject that was mentioned during the discussion of all the guidelines was the importance of positive reinforcement. One comment was that when the daily goal is reached that should be presented to the users in a very positive way

> "You probably should have a lot of balloons or something when you have reached a high goal."

Also, it was suggested to include physical medals that the users could get from a caregiver.

> "You get the collection of the different medals so that you can show your friends, but to that, the idea of having physical representation which possibly the caregivers could have, for the ones that value a more physical object, could be an interesting way to look at it as well. So if they got it on their app, they could get a physical medal from the caregiver."

That way, it would be easier to include the ones who are not easily motivated by virtual objects or rewards as that could also vary.

When talking about the involvement of caregivers, the two therapists agreed

> "I just think it's important that communication through the apps, [..] that they [the people with intellectual disabilities] handle this sort of applications [themselves], and not the caretaker."

> "Yes, so this communication, and making [sure] that the users are part of this app, its not something for the caregivers, its *their* application"

That means some users can find motivation just from being able to use the application themselves, without much assistance from a caregiver. This makes it essential to tailor the application around the user groups needs and wishes.

The final question asked by the authors was regarding communication, and the use of symbols, for example, only images or more text? One participant said

> "I don't think you should have more text, are those [the AAC images] animations, or are they static images?"

Responding that they are static images, symbols used in another application for people with intellectual disabilities, the participant continues

> "Yes, most of these people [with intellectual disabilities] are capable of learning what these symbols mean"

Using symbols as a way to support communication was also recommended, as most people with disabilities would be capable of learning what those symbols mean. It was encouraged to use symbols already established in institutions or schools in Norway.

The following table 6.2 summarizes the most valuable findings from the focus group based on the different themes discussed.

Theme	**Findings**
Functionality	• Good to base the activity goals on recommendations from the World Health Organization • Allow the physical activity goal to be customized to the individual • Make sure a caregiver have the possibility of hiding unsafe activities from the user • Only use positive reinforcement when trying to motivate the user • Use notifications to keep the user engaged and to motivate during the day • Keep the notifications relevant
Design	• Allow the different users to select activities they like to do • Focus more on the application being easy to understand than it not being too childish. • Take care in illustrating the passing of time, use more than one way of showing it • Use a single flower instead of a bouquet • Do not use animations unless it is to help inform like for example showing the passing of time
Communication	• Focus on simplicity, it is important that the users feel that they can control and use the application themselves • Do not rely only on text, symbols and images are a great addition • Use symbols that are created to support communication

Table 6.4: Findings from the focus group

6.3 User group observation

Following the focus group, the authors were invited to visit the day habilitation center where user testing would later take place. This was to get a better understanding of how the center works with people with intellectual disabilities, and what they can offer to the users.

The center is a day habilitation center in Trondheim, Norway, where people with different levels of intellectual disabilities can visit during the day for various therapies (sensory, aromatherapy), work experience or different organized activities.

During the visit, an activity therapist working at the center gave a tour of the facilities which included different wards for different activities and how the center catered to user needs. The observations of the facilities combined with the knowledge of the therapist giving the tour gave the authors valuable insight in the possible everyday life of people in the user group, as well as input on the prototype.

It is imperative to acknowledge the vast individual characteristics of people with intellectual disabilities. At the day center, they can facilitate anything from 90-100 users every day, and both cognitive and physical abilities are mostly varied. Some users use a wheelchair and have very limited mobility; some are not able to move unaided, while others can walk or cycle to the center. On the cognitive level, some have a very *young mental age* and require more supervision than others, while some are highly independent.

The center offers work experience, doing different tasks, i.e., assembling cardboard boxes for a garden center, making *fire starting kits* using old newspapers. There is a wood shop where make road markers for Vegvesenet[1]. Doing manual work, feeling like they are contributing and then seeing the results of their work gave a sense of meaning and are highly rewarding for the users doing work experience and training. The work experience might seem repetitive and tedious for a person without intellectual disabilities, but for the people who are working there, work was rewarding in itself, and the repetitive and predictable work tasks gave many of them a feeling of independence, confidence and being

[1]The Norwegian Public Roads Administration

in control.

In addition to the areas intended for work experience, the center also had facilities for different hobby activities, arts and crafts, a music room as well as a room for playing video games. There were separate rooms to unwind and relax when the users needed to; the rooms were customized for different needs regarding color, interior, and decorations.

Many people seemed to come to the center mainly to feel a sense of *everyday life* like going to work, but there are also other activities they could join like dancing, organized walks or hikes, singing, yoga and movie nights. Socialization and the feeling of community seemed to be a highly motivating factor for most users.

After the tour was finished there was a short, unstructured interview with the activity therapist to get a second opinion on the observations as well as some more questions about the people attending the center.

The activity therapist confirmed the impression that providing repetitiveness and predictability is not necessarily a negative thing when working with this group of people, and that the feeling of doing normal things like having a job was highly rewarding.

Also, the impression that socialization seemed like an essential factor for motivation and participation in activities was confirmed. The introduction of a new activity was used as an example. It takes some time, but as soon as a big enough group of people participates - many others want to join too. They also mentioned that competition was a factor that could either motivate or discourage someone, so competition as a strategy alone can be challenging when it comes to including many people.

When asked about mobile phone usage they said the use of smartphones is very individual among the people at the center, and that a challenge that is important to consider is not only the cognitive ability but the motor skills and physical ability to handle and operate the application.

Concluding the talk was some questions asked about testing and evaluating a mobile application on this user group. Firstly, should developers introduce and present the application, or should it be someone they already know and trust?

> "It should be possible to adjust this to the individual that is participating. Some can be a little reserved to strangers while others would think it was exciting. The users should also be able to try out the application themselves in the company of a caretaker, and get help and instructions when needed."

The last question was regarding how to test for usability in this group of people. They answered that when asking for an opinion from this user group, it is often very binary, i.e., very good or very bad. It is also a possibility that they will say they like it to please the one asking. Leading questions should be avoided, but beware it can still be hard to get real, honest feedback from these users. They suggested observing how the users interact with the application in addition to the questionnaire about usability.

Summarizing the observations, the authors find that repetitiveness and predictability is good, it gave the users a sense of independence. Socializing and competing with friends was a source of motivation for activity, but one should be cautious using competition, as it does not suit everyone. The user group can have very varying experience with mobile phones. It can be difficult getting reliable feedback in a user test setting, as some can say what they assume you want to hear. Doing a user test by observing and then having follow-up interviews with a questionnaire was supported.

Chapter 7

Contribution

It is important to separate the research and development in the earlier chapters from the contributions to knowledge, described in the following sections. The contribution chapter is also separate from the findings, as the findings themselves have been used in revising the final contribution, which is;
7.1; Guidelines for developing applications to promote physical activity in people with intellectual disabilities.
7.2; An adapted test framework to evaluate the developed application on people with intellectual disabilities.
7.3; Guidelines resulting from the work and research required for the NSD application. These are guidelines for applying for ethics approval in IT projects needing to interact or do user testing with people having intellectual disabilities.

7.1 Application Development Guidelines

The following section describes the suggested guidelines for developing mobile applications for people with intellectual disabilities, especially focused on increasing daily physical activity. The different guidelines are described and explained in more detail in chapter 8.

7.1.1 System functionality

Guideline	**Example use**
Allow the application to have a slower pace than usual when developing for the general population	Allowing the user to select their own goal, instead of starting with the WHO recommendations right away
All activity counts towards the main goal, based on WHO recommendations (The goal can be active time or steps, and should be customizable)	Have the application track activity even when it is not actively onscreen
Allow for different activities to be chosen, i.e., running, walking, dancing	The activity home screen in the revised prototype allows a user to choose their preferred activity
Make sure some activities can be hidden from the users as not all activities are safe (i.e., hide the activity "swimming" if the user cannot swim)	Give a caregiver and the user the option to hide activities from the settings
Encourage doing activities together with others	The user can view their friends' achievements as well as invite them to participate in their dancing activity
Use notifications to keep the user engaged	Remind the user that there is still time to make the flower bloom
There should be a reward system	The flower blooms, and the user receives a medal

Table 7.1: Revised system functionality guidelines

7.1.2 Design

Guideline	Example use
Keep it simple. Limit the information on each page or view	The activity screen displays the necessary information in a simple way, without to many interfering visual elements
Limited use of color	The revised prototype uses a simple color scheme consisting of two main colors
Use high contrast	The text used throughout the prototype follows the WCAG standards for contrast
Limit the use of animations, blinking and too much activity on a page/view	In the revised prototype, the only animation used is the flower blooming and the progress bar changing as the user approaches their goal
Let colors, font size and contrast be adjustable	Allowing the user to choose their own font-size and color scheme

Table 7.2: Revised design guidelines

7.1.3 Communication

Guideline	Example use
Simple, non-ambiguous language	Using single words to describe the different activities
Use the native language of the user	The language used in the revised prototype is Norwegian, as testing was planned around Norwegian users.

Use suitable aids to support communication	Using Augmented Alternative Communication images alongside text
Avoid the use of numbers, graphs or charts to communicate progress	In the revised prototype, progress is displayed using a flower blooming
When showing the passing of time, use supportive communication aids	In the revised prototype, the time passed while doing an activity is symbolized by using a large progress bar and the blooming flower
Take advantage of appropriate standards if available[1]	The revised prototype uses single words alongside images to convey information
Represent real people with pictures instead of symbols or avatars	The revised prototype displayed in this thesis uses drawn pictures, but this is due to privacy issues. In a real-world setting, these pictures would be of the actual users

Table 7.3: Revised communication guidelines

7.2 Adapted Test framework

This section describes the proposed guidelines to be used when evaluating mobile applications for people with intellectual disabilities. Generally, it is recommended to start recruiting participants early, as the degree of the cognitive and physical disabilities in this population is highly varied.

1. Start with an introductory conversation with the participant, explaining the project, their potential involvement, and what participation would mean for them

[1] EU and Norway's "easy to read" standards

2. Perform a semi-structured interview with the participant to map existing knowledge of mobile phones, potential background information that can be relevant for the application to be tested

3. Present the application by explaining the purpose and the functions

4. Observe the participant interacting with the application, observation time depending on the type of application

5. After the observations, do another unstructured interview, to allow the user to tell their experiences and confirm or dismiss assumptions from the observations. An interview with a caretaker/parent can also be used to support the observations

6. Use an adapted questionnaire to help guide the interview, and to generate data that can be used quantitatively

7.3 Ethics Application Guidelines

Resulting from the work towards gaining approval from NSD, the authors propose the following guidelines for applying to the NSD in IT projects where there will be involved people with intellectual disabilities. The approval document from the NSD advisors can be found in the appendix C.2 The guidelines are further discussed in section 8.3.

1. Apply for individual projects separately when possible, especially if any of the required documentation will differ between the projects

2. Start early, preferably as soon as the methodology is chosen and the test framework is created

3. Do not make any assumptions about whether the person assessing the application will have the same understanding of the project you do. They will only know what you tell them about the project

4. Carefully consider what personal information is needed to complete the research

5. Do not assume a low amount of feedback on an application denial means there are few issues to take care of

6. Use the messaging function of the online application form if there is something that seems unclear, or if there is not a suitable place in the application to describe the intention of a decision

7. Carefully consider if you need to include compliance from third parties or not

8. Use precise and clear communication when interacting with NSD privacy advisors

9. Use the principals provided by *The National Committee for Medical and Health Research Ethics*[2] on including people with reduced or no ability to consent.

10. Limit privacy loss as much as possible when including people without the ability to consent. Focus on providing adapted information

[2]https://www.etikkom.no/forskningsetiske-retningslinjer/Medisin-og-helse/Redusert-samtykkekompetanse/Generelle-prinsipper/

Chapter 8

Discussion

This chapter is meant to be a review of the work that has been done, and here the authors discuss methods of the project, the findings, and the contribution.

The methods used in this project worked well. In retrospect, if anything were to be changed, it would be to include experts earlier in the process to evaluate the prototype. This change is a result of the NSD application taking far longer than expected, which meant the authors had minimal time in recruiting participants for user testing. After recruiting two potential user test groups with 4 participants in each, user testing was to take place late April or early May of 2019. Unfortunately, both groups backed out of user testing just before the start of May. As a result of this, the intended research and development flow deviated from the plan described in figure 2.2. To illustrate these changes, figure 8.1 show the actual research and development flow of this thesis.

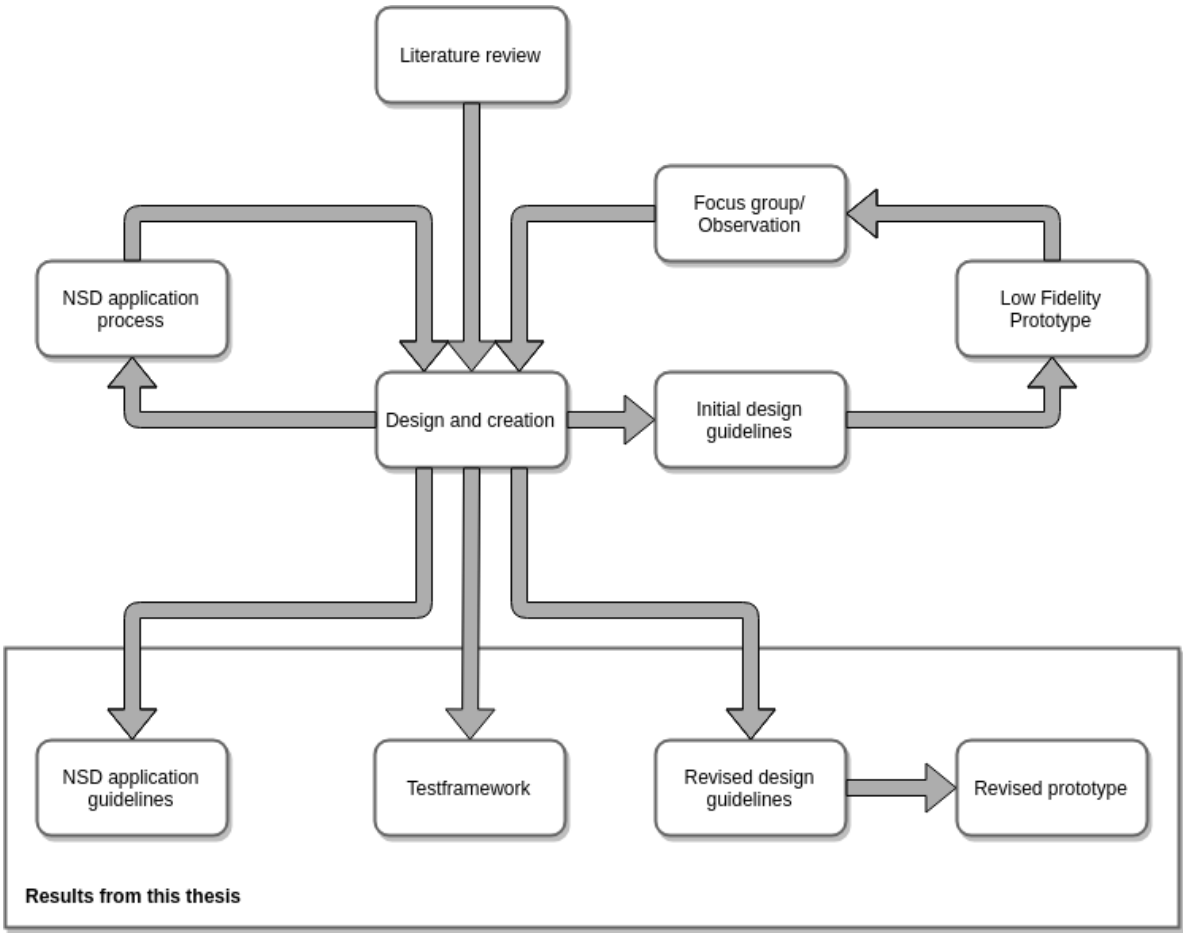


Figure 8.1: Revised research and development flow

8.1 Application Development Guidelines

Functionality

The reasoning behind recommending a slower pace is to accommodate users having limited ability in the processing of information, sensory impressions and may have a longer reaction time. These decisions are based on characteristics of the diagnosis of intellectual disabilities World Health Organization (2016); Lorentzen (2008), and was supported by participants in the focus group. Using the recommended activity levels set by the World Health Organization as a goal was also supported, as this application is meant to be a tool

in trying to overcome health challenges, not create athletes. Allowing the goals to be customized can mean including a larger group of people. It would allow sedentary users an easy start and a way to work towards the recommended levels of activity. Reaching higher levels of physical activity can reduce many health risks. Even a small change in daily activity levels can help a user achieve health benefits.

Having the different activity suggestions available is to make sure as many users as possible can find an activity they are motivated for, as preferred activity vary a lot between this user group as in any other. There should not be too many options available, one participant in the focus group made the argument that if a user enjoys several activities (more than 5) they are more likely to do more physical activity than their peers, and they might be overwhelmed by getting too many suggestions and options to choose from. A significant point being raised during the focus group was the safety aspect when having different activities to choose from. One of the participants made the authors aware that having i.e. swimming as a suggestion for a user that can not swim can pose as a safety risk, so there should be a way for a caretaker/parent to control what activities are available for each user.

Social reward and being together with other people was the most commonly occurring facilitator and motivator for doing physical activity in existing research Kuijken et al. (2015); Temple (2009); Bossink et al. (2017), and was also supported by the focus group participants, and during the observations where most activities at the day center were possible to do in groups. The recommendation is to include some form of social interaction in the application, whether it is being able to invite friends to do an activity, being able to support each other or compete against your friends. An important note is that cooperation and being supported was a more common facilitator than the element of competition which might not be for everyone. This was also confirmed during the observations.

Using notification is one of the most used functions to get users to stay engaged and invested in the application, as shown in the study by Kuru (2018), reviewing techniques for behavioral change using applications to promote physical activity. The participants of the focus group also asked about the use of notifications, saying many users would need to be reminded and to get positive reinforcement throughout the day to stick with it. Posi-

tive reinforcement was also identified as a facilitator by many studies during the literature review Melville et al. (2015); Badia et al. (2011); Bodde and Seo (2009), which affects both notifications and the reward system. The result of the focus group regarding rewards is to give them frequently and make them look like something out of the real world, like medals or badges. This idea came from the studies identifying working towards a goal or getting a medal/prize as a motivator for physical activity Temple (2009); Bossink et al. (2017), and also the existing commercial applications described in section 3.3. Having a digital representation of the medal or badge may not be as rewarding as a physical one for some users, so there was the suggestion of having real medals that a caregiver could give the user when reaching a goal, which might be a solution to investigate in the future. The prototypes feature of having the flower change state from closed to open was discussed as a potential reward in itself in the focus group, as it is something that the user can change by interacting with the application.

Design

Keeping it simple and limiting the amount of information of each view or page has the same reasoning as the slow pace for functionality. Mental processing and cognitive abilities are different, and there might not be a need for a fast-paced information-packed application. This was clear while doing the observations at the day center that many of the clients there had a preference for tasks and activities that seem tedious and repetitive for someone without intellectual disabilities. That is why design should focus on getting the information across effectively and appropriately instead of making a visually pleasing interface.

As it is good practice to ensure accessibility in any application development, interfaces should have high contrast. When using colors, validate sufficient contrast using tools based on WCAG requirements, for example, the "Color Contrast Checker" provided by WebAIM Web Accessibility in Mind (WebAIM) (2019). Allowing the font size, use of colors, and contrast to be adjustable by each user also help to make the application more accessible. In the focus group and during the observations, this was also pointed out as necessary

since people with intellectual disabilities may have physical disabilities too, or limited fine motor skills.

Limiting the use of animations, flashing, blinking, and activity on one page or view is also to help make it simpler to use. Having too much visual information or sensory input at once can be overwhelming, and animations should be used as a communication aid instead of using animations to make a more impressive or aesthetic view.

Communication

As language is a difficult skill for many people with intellectual disabilities, all text-based information should be kept simple and unambiguous. Using standards like the "Easy to read" Inclusion Europe (2019) or "Informasjon for alle" NFU (2019) in Norway is advised, as well as always letting all text be in the intended user's native language. All written information should be non-ambiguous, as metaphors and literary images are not easy to understand and can be confusing.

Representing people with pictures is also to avoid abstraction, and it is also the reasoning behind preventing the use of numbers, graphs, and charts to show progress. *Assisting augmented communications* should be used where appropriate, meaning that you would try and communicate the information in more than one way. When describing the passing of time, doing so with both symbols of a clock and a progress bar is better than, i.e., just using numbers counting down. This solution was thoroughly discussed during the focus group when handling the subject of communicating the passing of time. Generally, all participants having work experience with people with intellectual disabilities told that time is a challenging subject for them. For many, there is only *right now* and *later* with later possibly being 20 minutes later or the next day. When trying to motivate the users to do an activity for a certain amount of time, it is vital to show the passing of time in more ways than one.

When deciding on what symbols to use to support communication, the authors recommend using whichever symbol systems already are in use in the country, county, city, or community where the users are. As stated during the focus group, people with intellec-

tual disabilities have a high capacity of learning symbols like this, and therefore it is even better if the symbols used are ones the users are already familiar with. When deciding on which symbols to use in this application development, the most commonly used in Norway was evaluated, and the description with pros and cons, where applicable, is included in appendix B.2

8.2 Evaluation and Test Framework

The adapted test framework developed in this project aims to evaluate the developed application for perceived usefulness in the intended user group, rather than the effect on the user's physical activity. Wiemeyer et al. (2015) also says tests for usability, acceptance, and validation among users should come before efficacy tests, which agrees with the approach of the developed test framework. The study also recommends that when developing applications for people with disabilities, it is important to include the users early in the development. Another reasoning for the early involvement of the users is that a study by Melville et al. (2015) showed that simply using a physical activity program or intervention that has proven efficacy on the general population, not necessarily will give the same results in people with intellectual disabilities. This further supports the need for intended users being part of the iterative development process early, as adaptions and changes can be made between iterations rather than to the finished application.

As several studies show, recruiting participants for research with intellectual disabilities can be a real challenge, both in getting enough participants and recruiting within sufficient time for the time frame of the project. As a result of this, a recommendation is to start recruiting early as previous studies show that recruiting users in this group of people who have the required level of cognitive ability and at the same time are physically able, can be difficult and time-consuming Melville et al. (2015); Oviedo et al. (2014); Hilgenkamp et al. (2012). Researchers should try to recruit across fields and institutions to acquire a large enough sample size Wiemeyer et al. (2015). George et al. (2014) mentions that it can be difficult to get useful feedback from the user group alone, as experience with mobile

technology is so varied, and getting quantitative data by using, i.e., questionnaires can be hard. This is supported by findings from the observations. Therefore, the evaluation would be through combining observations and a semi-structured interview with the users to help eliminate bias and assumptions, and also help against the users saying one thing while doing the other. An adapted questionnaire is a useful tool when conducting an interview with recruited participants. This approach was supported by the activity therapist at the day habilitation center, where the user testing originally was meant to take place. As mentioned by George et al. (2014) a fine-grade scale is challenging to use when testing on people with intellectual disabilities, so for the user tests, a questionnaire was created taking inspiration from the SUS[1]-questionnaire Brooke et al. (1996). Since it was changed as much as it was to accommodate the cognitive levels of participants, it would not be possible to utilize the usability calculations provided through the SUS-questionnaire. These changes mean the data generated from user testing would be mainly qualitative, but the use of a questionnaire still makes an effort towards a usability score that can be quantitatively measured.

8.3 Guidelines for obtaining Ethics approval

The recommendation for submitting the applications separately aims to avoid confusion when two projects potentially use different methods and need different information and data. Another issue is that one project might have been approved before the other project if the applications were made separately. Another factor is that only one person can use the online portal for the application, meaning the application submission (and potential re-submission), uploading documents and communicating with the NSD advisors have to be done by one person on behalf of all the different projects. As long as the applications need separate uploads to support data collection, the authors highly advise on applying separately.

Considering what personal data collection is needed is crucial to fill in the application

[1] System Usability Scale

appropriately. As long as data that can in some way be used to identify a person directly is *stored, written, or recorded*, you need a separate information letter and recorded consent[2].

There were special challenges for this project, stemming from GDPR and the new rules and regulations. Since NSD advisors evaluate a lot of different projects, not only regarding IT, assuming they will know the domain as well as you do is unreasonable. Explain using layman's terms whenever possible. In this project, communication issues like this are illustrated by the authors trying to justify the use of NTNUs own servers that are hosting the data stored on Microsoft's cloud services such as SharePoint and OneDrive. Trying to explain the reason this was safe storage to someone not familiar with it almost resulted in the authors needing a letter from Microsoft confirming that the data was stored safely.

Even if there are multiple issues needing to be addressed on an application, the advisors can deny the application based on just the first issue they find without going through the application as a whole. Applicants should be prepared for more requirements to be presented by the advisors during the application process.

Unless the people considered to be defined as *third parties* is directly identifiable from what you record, write down or store, it is not necessary with consent or information letters for the third party. There is a potential of a participant in research mentioning another person by name, this is not considered enough for the named person to count as a third party, but the name should still be excluded from all records and stored data.

If any misunderstandings or unclear information leads to a denied application, this results in the application form having to be resubmitted, even when there are no changes to the application. The application will, however, not be pushed to the back of the line, but it still needs to be resubmitted manually every time there is a new requirement in the application.

In general, since the revised prototype was meant to be evaluated using people with intellectual disabilities, steps had to be made to minimize the participant's potential privacy loss. Among the measures taken to reduce the potential privacy loss was writing a separate information letter with adapted language using guidelines from the easy to read

[2]Written down or recording of spoken consent

standard NFU (2019), including a separate section for them to express written consent, even though signing is not legally valid. The focus was primarily on what it will mean for them to participate and focusing on that participation is voluntary and can be withdrawn at any time.

Although the NSD application process required much time and work not directly related to development, valuable information came out of the application process related to communication with the user group.

8.4 Limitations and critique

The main limitation to the contribution is the revised prototype missing feedback and input from the intended users. Obtaining expert opinions through a focus group and having some interaction with the intended user group through the observation became the only evaluation. This as a result of the two user test groups backing out. Both Wiemeyer et al. (2015) and Edler and Rath (2014) discusses the importance of user-centric design and user involvement when designing for people with disabilities. Due to the NSD notification being approved so late, recruiting users were postponed until the last few months. This resulted in the last iteration of the prototype development was not completed. This iteration was to include a user test. Recruiting participants from this user group is hard, as shown in the studies by Peterson et al. (2008), who had 39% response rate by invitees, and Wiemeyer et al. (2015) who spent 13 months recruiting enough participants. In addition to it being hard to recruit in general, this project had to do it in a minimal time frame which meant many would decline or not give an answer in sufficient time.

After finding two groups that were recruited through the focus group and project network, both unfortunately backed out after scheduling user tests in late April. From this experience, the authors would have done two things differently;

(1) Start contacting potential participants through appropriate institutions earlier, and even before the NSD application was approved to have an established contact to build on when the notification was accepted.

(2) Although user testing was planned, the authors should have arranged expert interviews to give final feedback on the revised guidelines and prototype. This way the contributions would include two separate evaluations, and there would be multiple ways to validate the findings in the case of unforeseeable circumstances that would impact one of the planned evaluations.

Obtaining the NSD notification approval was a greater challenge than anticipated at the start of the project. As the user group requires adapted information and there needed to be a justification of the projects data collection, a lot of time was spent on researching appropriate use of language and how to interview and test with people having disabilities, which meant less time spent on research and development on the actual application. In retrospect, the authors would, of course, start the notification process earlier, but the consent form and information letters required information about the system that was going to be tested, and therefore it was not feasible to do the notification until at least the first low-fidelity prototype was ready to be used as part of the information letters.

Chapter 9

Conclusion and future work

There were two main research questions of this thesis. The first one was to identify ways to create mobile applications that promote physical activity in people with intellectual disabilities. The second one was to identify a way to evaluate these applications.

The first research question was explored using a literature review to gain insight into what was a new field for the authors. The initial development guidelines and the low fidelity prototype was based on the findings of this literature review. A focus group was then held, where the topics of discussion were the initial guidelines and low fidelity prototype. Based on this, the revised development guidelines and revised prototype were developed.

Following the focus group, the second research question was explored. A user test was planned and was based around observing recruited participant from the user group interacting with the prototype. A follow-up interview would be conducted to allow the participants to comment on the authors' observations, as well as provide any additional feedback on the usability and usefulness of the prototype. Unfortunately, the user test was never performed because of the two test groups backing out.

Due to the missing user test, the background for our conclusion regarding the first research question is based on the literature review, the focus group and observations. The participants in the focus group agreed that our proposed guidelines were a good tool for the development of mobile applications tailored for people with intellectual disabilities.

The participants also provided useful feedback and suggested improvements. Based on this, we conclude that our revised guidelines are an excellent tool to use, both before and during, development of mobile applications to promote physical activity for people with intellectual disabilities.

The adapted test framework, developed as part of this thesis, has been an effort to answer the second research question. This framework is based on the findings of the literature review focusing on technology and people with intellectual disabilities. The focus group and observations also provided considerable contributions to the adapted test framework. Thus we conclude that the main focus for testing gamified mobile applications with individuals having intellectual disabilities, should be on users' perceived usefulness of the application, before any efficacy testing is conducted. Building on this, we strongly recommend that any testing follows an adapted test framework, such as the one presented in this thesis.

9.1 Future work

In the future, it would be interesting to see the application fully developed utilizing the proposed guidelines and involving users for evaluation of the usability. Following this, it would be possible to start efficacy testing where the application's impact on daily physical activity could be adequately tested. This efficacy testing needs to be planned and executed in a manner that would minimize weaknesses from earlier physical activity interventions in the user group. This includes having a control group, a sufficient number of participants and follow up controls to check if the results were permanent or if the participants reverted to the state they were in before the intervention.

Another exciting potential for future application development is to explore the possibility of adapting the guidelines and application to be used by children. As the guidelines presented in this thesis are customized to individuals with a potentially lower cognitive age, it would be interesting to see if the work can be easily transferred to motivate children to be more physically active.

Appendix A

I3E-DTIS Conference paper

Designing game-inspired applications to increase daily PA for people with ID

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Abstract. People with **intellectual disabilities** are less likely to meet the recommended daily levels of **physical activity**. Meeting these requirements can lower the risk of serious health problems and life threatening diseases. To address this **problem**, the **idea** is to exploit mobile applications designed specifically to help increase daily levels of physical activity.
The **results** are: **guidelines** developed by a **literature review** and lessons learned during the development of a **prototype** application. **Evaluation** issues are based on focus group and usability test.

Keywords: Physical activity · Intellectual disabilities · Mobile Applications · Gamification · e-Health.

1 Introduction

Cognition is the "mental action or process of acquiring knowledge and understanding through thought, experience, and the senses" [3]. Intellectual disabilities (ID) falls under the term cognitive disabilities, but there is no international standard to what it means to have an ID. The Diagnostic and Statistical Manual of Mental Disorders (5th edition) says intellectual disability means a significant deficit in adaptive skills and carrying out age-appropriate daily tasks[19]. The World Health Organization (WHO) uses IQ and defines intellectual disability as having an IQ under 70, although meeting this requirement is not enough for a diagnosis. A diagnosis requires further tests in motor and social skills, language and social interaction and the handling of everyday tasks[24].

Among people with IDs, studies has discovered very low levels of physical activity [14][20][21] with only a small percentage meeting recommended levels of physical activities set by both global and national health organizations [1][2]. According to the World Health Organization (WHO), all adults between the age of 18-64 years old have the same recommendation for minimal level of physical activities per week;*at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week*[1]. Evidence shows that meeting these requirements can result in an overall lower rate of life-threatening diseases such

as coronary heart disease, high blood pressure, stroke, different types of cancer and depression. Physical activity will also help reduce the risk of becoming overweight and the increased health risks that brings[15].

Among technologies used to create and support solutions for health benefits (eHealth) the use of mobile technology is growing fast[13][16]. The term mHealth (mobile health) covers *The use of mobile and wireless technologies to support the achievement of health objectives*[16]. Mobile phones are a potential platform for serious games, which in recent years have become an increasingly valid medium for solving challenges in the fields of education and healthcare[23][11]. Serious games have been used to support rehabilitation, to promote healthy lifestyles and have shown effectiveness as a training program[12]. *The practice of making activities more like games in order to make them more interesting or enjoyable* is called gamification[4]. Mechanics from gamification used in eHealth are for example rewards, feedback and sozialisation[18].

2 Related work

In this section we are going to present the most relevant academic work that address the problem of physical activity of people with ID.

2.1 Related research

As people with IDs are more sedentary than people without IDs, several studies have examined the motivators and barriers for physical activity in this population [21][9][20][10][17]. These factors are very individual and varied, but certain common motivators and barriers has been identified and should be considered;
Motivators; Social interaction, working towards a goal, feeling healthy, having work that requires PA & competition
Barriers; Lack of facilities for PA, lack of support from key support persons, cost of activities, enjoying unhealthy food and activities & lack of guidance.

The Web Accessibility Initiative (WAI)[6] have some examples on potential barriers for people with cognitive disabilities when using technology. Their guidelines WCAG 2.0 (Web Content Accessibility Guidelines)[7] have several requirements to fulfill in order to create an accessible application.

When designing applications for people with disabilities, accessibility (i.e operating the application, perception of events and requirements of use) needs to be considered[22]. Another point to keep in mind should be that when designing applications for adults, one should avoid designing the application as if it is intended for children[5].

The Diagnostic and Statistical Manual of Mental Disorders (5th edition)[8] describes different levels of intellectual disabilites and the impact on conceptual, social and practical domain. Understanding written communication and abstract ideas can be difficult in varying degrees for people with IDs, meaning abstract thinking and executive function is impaired.

Information for all[5] is an European standard helping anyone trying to communicate information to make it accessible to everyone. The standards are describing how to use words, sentences, fonts and images. As many can find it hard to read text, the standards suggests the use of images to support the information trying to be communicated.

3 Proposal

3.1 Suggested guidelines

Based on the review of related works, the authors suggest to keep the following guidelines in mind when designing game-inspired mobile applications for the user group.

Functionality The functionality of the applications should focus on supporting the motivators and counteracting the barriers outlined in section 2.1. By having the option to interact with family and friends, social interaction and competition can be achieved. At the same time strengthening the support and guidance from key support persons. Rewards in the form of medals or achievements is also encouraged to further promote social interaction and working towards a goal. Where possible, developers should attempt to limit the required hardware to devices the users already have access to, in order to decrease the cost of activities. The level of customizability should also be considered. Having key support persons be able to suggest or decide what activities are available to the disabled user, could have a positive impact on the daily level of physical activity as they are performing activities they enjoy.

Design The design of the applications should focus on conveying clear, unambiguous information to the users. Information should be presented in limited quantities per view, considering font size, color-use and contrast, as discussed in section 2.1 and outlined by WCAG [7].

Communication The *European standards for making information easy to read and understand*[5], provides a high number of rules to consider. Many of which can be directly included into development of applications designed for people with IDs. Highlighting a selection of them, it is suggested to keep sentences short and to use simple words. Larger numbers and percentages should be avoided. Images are a good way of conveying information, either alongside text, or alone.

3.2 Initial prototype

Figure 1, 2 and 3, illustrates the main flow of an early prototype application utilizing the guidelines proposed in 3.1.

Figure 1 shows the screen that would greet the user before the daily activity goal is reached. As suggested by WAI[6], the amount of information provided is limited in order to make the main objectives of the view clear. The available activities are described using a single word, accompanied by an image as suggested in *Information for all*[5].

Instead of using a step-counter or progress-bar, the progress of the daily activity is symbolized using a flower that blooms as you get closer to the daily activity goal. Figure 3 shows the flower in full bloom, symbolizing that you have met your daily goal.

Figure 2 is displayed while the user is active and shows the flower changing, in order to motivate them to keep going. The data is also displayed in a similar way throughout the application in order to make it easier to understand.

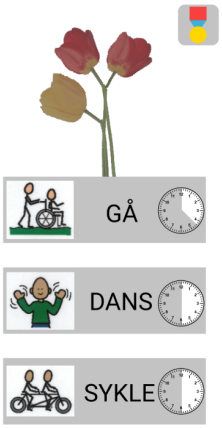

Fig. 1: Before activity

Fig. 2: During activity

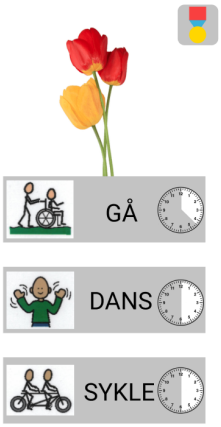

Fig. 3: After activity

4 Evaluation and future work

The prototype and the guidelines will be evaluated using a focus group, and later tested with a selection from the user group.

4.1 Focus group

The guidelines purposed in section 3.1 will be discussed in a focus group containing experts from different fields. These include people with experience in working with the user group as well as people with experience in development of mobile applications and games.

4.2 Prototype game

The prototype game will be further developed based on the feedback of the focus group. The improved prototype will then be tested with a selection of the user group. The results and observations gathered from this test will be the basis of data in the larger project, that will attempt to answer the question of whether or not such applications can be a motivating factor towards an increased level of daily physical activity in the user group.

4.3 Ethics

In order to complete the suggested usability test, temporary storage and analysis of personal data is required. The necessary applications has been made and approved by both NSD (Norwegian Center for Research Data) and REK (Regional Committees for Medical and Health Research Ethics)

Conflict of Interest The authors declare no conflicts of interest

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Henriette Michalsen `<henriette.michalsen@uit.no>`

References

1. Physical activity and adults (Jun 2015), https://www.who.int/dietphysicalactivity/factsheet_adults/en/
2. Anbefalinger fysisk aktivitet (July 2016), https://helsedirektoratet.no/folkehelse/fysisk-aktivitet/anbefalinger-fysisk-aktivitet
3. Definition of cognition in english (2018), https://en.oxforddictionaries.com/definition/cognition
4. Definition of gamification in english (2018), https://dictionary.cambridge.org/us/dictionary/english/gamification
5. European standards for making information easy to read and understand (2019), https://easy-to-read.eu/european-standards/
6. W3, wai, funtamentals; accessibility intro (2019), https://www.w3.org/WAI/fundamentals/accessibility-intro/
7. Web content accessibility guidelines (wcag) 2.0 (2019), https://www.w3.org/TR/WCAG20/
8. Association, A.P., et al.: Diagnostic and statistical manual of mental disorders (DSM-5®). American Psychiatric Pub (2013)
9. Bodde, A.E., Seo, D.C.: A review of social and environmental barriers to physical activity for adults with intellectual disabilities. Disability and Health Journal **2**(2), 57–66 (Apr 2009). https://doi.org/10.1016/j.dhjo.2008.11.004

10. Bossink, L., van der Putten, A.A., Vlaskamp, C.: Understanding low levels of physical activity in people with intellectual disabilities: A systematic review to identify barriers and facilitators. Research in Developmental Disabilities **68**, 95–110 (Sep 2017). https://doi.org/10.1016/j.ridd.2017.06.008
11. Crookall, D.: Serious games, debriefing, and simulation/gaming as a discipline. Simulation & gaming **41**(6), 898–920 (2010)
12. Graafland, M., Dankbaar, M., Mert, A., Lagro, J., De Wit-Zuurendonk, L., Schuit, S., Schaafstal, A., Schijven, M.: How to Systematically Assess Serious Games Applied to Health Care. JMIR Serious Games **2**(2), e11 (Nov 2014). https://doi.org/10.2196/games.3825, http://games.jmir.org/2014/2/e11/
13. Gurman, T.A., Rubin, S.E., Roess, A.A.: Effectiveness of mhealth behavior change communication interventions in developing countries: a systematic review of the literature. Journal of health communication **17**(sup1), 82–104 (2012)
14. Hilgenkamp, T.I., Reis, D., van Wijck, R., Evenhuis, H.M.: Physical activity levels in older adults with intellectual disabilities are extremely low. Research in Developmental Disabilities **33**(2), 477–483 (Mar 2012). https://doi.org/10.1016/j.ridd.2011.10.011, http://linkinghub.elsevier.com/retrieve/pii/S0891422211003908
15. III, H.W.K., Cook, H.D. (eds.): Educating the Student Body: Taking Physical Activity and Physical Education to School. The National Academies Press, Washington, DC (2013). https://doi.org/10.17226/18314, https://www.nap.edu/catalog/18314/educating-the-student-body-taking-physical-activity-and-physical-education
16. Kay, M., Santos, J., Takane, M.: mhealth: New horizons for health through mobile technologies. World Health Organization **64**(7), 66–71 (2011)
17. Kuijken, N.M.J., Naaldenberg, J., Nijhuis-van der Sanden, M.W., van Schrojenstein-Lantman de Valk, H.M.J.: Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives: Perspectives of people with ID on healthy living. Journal of Intellectual Disability Research **60**(3), 228–241 (Dec 2015). https://doi.org/10.1111/jir.12243
18. Sardi, L., Idri, A., Fernández-Alemán, J.L.: A systematic review of gamification in e-health. Journal of Biomedical Informatics **71**, 31–48 (2017)
19. National Academies of Sciences, E., Medicine, et al.: Mental disorders and disabilities among low-income children. National Academies Press (2015)
20. Temple, V.A.: Barriers, enjoyment, and preference for physical activity among adults with intellectual disability. International Journal of Rehabilitation Research **30**(4), 281–287 (Dec 2007). https://doi.org/10.1097/mrr.0b013e3282f144fb
21. Temple, V.A.: Factors associated with high levels of physical activity among adults with intellectual disability. International Journal of Rehabilitation Research **32**(1), 89–92 (Mar 2009). https://doi.org/10.1097/mrr.0b013e328307f5a0
22. Wiemeyer, J., Deutsch, J., Malone, L.A., Rowland, J.L., Swartz, M.C., Xiong, J., Zhang, F.F.: Recommendations for the Optimal Design of Exergame Interventions for Persons with Disabilities: Challenges, Best Practices, and Future Research. Games for Health Journal **4**(1), 58–62 (Feb 2015). https://doi.org/10.1089/g4h.2014.0078, http://www.liebertpub.com/doi/10.1089/g4h.2014.0078
23. Wilkinson, P.: A brief history of serious games. In: Entertainment computing and serious games, pp. 17–41. Springer (2016)
24. World Health Organization: International statistical classification of diseases and related health problems, chapter v; mental and behavioural disorders, (f00-f99) (2016), http://apps.who.int/classifications/icd10/browse/2016/en/F70

Appendix B

Additional information

B.1 Literature review sources

Title	Authors	Year	Publication
Easy to surf - what makes websites accessible to people with intellectual and learning disabilities	Antener, G., Bolfing, A., and Calabrese, S	2014	Computers Helping People with Special Needs, pages 157–160, Cham. Springer International Publishing.
Diagnostic and statistical manual of mental disorders (DSM5®)	American Psychiatric Association and others	2013	
Personal factors and perceived barriers to participation in leisure activities for young and adults with developmental disabilities	Badia, M., Orgaz, B. M., Verdugo, M. A., Ullán, A. M., and Martínez, M. M.	2011	Research in Developmental Disabilities, 32(6):2055– 2063
A review of social and environmental barriers to physical activity for adults with intellectual disabilities	Bodde, A. E. and Seo, D.-C	2009	Disability and Health Journal, 2(2):57–66

Understanding low levels of physical activity in people with intellectual disabilities: A systematic review to identify barriers and facilitators	Bossink, L., van der Putten, A. A., and Vlaskamp, C.	2017	Research in Developmental Disabilities, 68:95–110
Randomized trial of a fitbit-based physical activity intervention for women.	Cadmus-Bertram, L. A., Marcus, B. H., Patterson, R. E., Parker, B. A., and Morey, B. L	2015	American journal of preventive medicine, 49(3):414–418.
Accuracy of smartphone applications and wearable devices for tracking physical activity data	Case, M. A., Burwick, H. A., Volpp, K. G., and Patel, M. S	2015	Jama, 313(6):625– 626
Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis.	Cooper, S.-A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., and Morrison, J.	2015	BMC Family Practice, 16(1):110
Physical activity levels in adults with intellectual disabilities: A systematic review	Dairo, Y. M., Collett, J., Dawes, H., and Oskrochi, G. R.	2016	Preventive medicine reports, 4:209–219.
Fitbit®: An accurate and reliable device for wireless physical activity tracking.	Diaz, K. M., Krupka, D. J., Chang, M. J., Peacock, J., Ma, Y., Goldsmith, J., Schwartz, J. E., and Davidson, K. W	2015	International journal of cardiology, 185:138–140.
People with learning disabilities using the ipad as a communication tool-conditions and impact with regard to e-inclusion	Edler, C. and Rath, M.	2014	In International Conference on Computers for Handicapped Persons, pages 177–180. Springer.
Are currently available wearable devices for activity tracking and heart rate monitoring accurate, precise, and medically beneficial?	El-Amrawy, F. and Nounou, M. I	2015	Healthcare informatics research, 21(4):315–320.

Testing the perceived ease of use in social media.	George, J., Dietzsch, N., Bier, M., Zirpel, H., Perl, A., and Robra-Bissantz, S.	2014	International Conference on Computers for Handicapped Persons, pages 169–176. Springer.
A review of weight loss interventions for adults with intellectual disabilities.	Hamilton, S., Hankey, C. R., Miller, S., Boyle, S., and Melville, C. A	2007	Obesity Reviews, 8(4):339–345.
Ageing and health status in adults with intellectual disabilities: Results of the european pomona ii study.	Haveman, M., Perry, J., Salvador-Carulla, L., Walsh, P. N., Kerr, M., de Valk, H. V. S. L., Hove, G. V., Berger, D. M., Azema, B., Buono, S., Cara, A. C., Germanavicius, A., Linehan, C., Määttä, T., Tossebro, J., and Weber, G.	2011	Journal of Intellectual & Developmental Disability, 36(1):49–60.
Evaluation framework for ict-based learning technologies for disabled people.	Hersh, M	2014	Computers & Education Volume 78, September 2014, Pages 30-47
Physical activity levels in older adults with intellectual disabilities are extremely low.	Hilgenkamp, T. I., Reis, D., van Wijck, R., and Evenhuis, H. M.	2012	Research in Developmental Disabilities, 33(2):477–483.
Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives: Perspectives of people with ID on healthy living	Kuijken, N. M. J., Naaldenberg, J., Nijhuis-van der Sanden, M. W., and van Schrojenstein-Lantman de Valk, H. M. J.	2015	Journal of Intellectual Disability Research, 60(3):228–241.
Behavior change techniques used in mobile applications targeting physical activity: A systematic review.	Kuru, H.	2018	Current and Emerging mHealth Technologies: Adoption, Implementation, and Use, pages 23–35.

Learning technologies for people with disabilities	Laabidi, M., Jemni, M., Jemni Ben Ayed, L., Ben Brahim, H., and Ben Jemaa, A.	2014	Journal of King Saud University - Computer and Information Sciences, 26(1):29–45.
Psykisk utviklingshemning - hvordan stilles diagnosen?	Lorentzen, E.	2008	"Tidsskrift for Den norske legeforening, 128(2):201–202."
Effectiveness of a walking programme to support adults with intellectual disabilities to increase physical activity: walk well clusterrandomised controlled trial.	Melville, C. A., Mitchell, F., Stalker, K., Matthews, L., McConnachie, A., Murray, H. M., Melling, C., and Mutrie, N.	2015	International Journal of Behavioral Nutrition and Physical Activity, 12(1):125
" easy-to-read on the web": State of the art and needed research	Miesenberger, K. and Petz, A.	2014	International Conference on Computers for Handicapped Persons, pages 161–168. Springer.
Effects of aerobic, resistance and balance training in adults with intellectual disabilities.	Oviedo, G. R., Guerra-Balic, M., Baynard, T., and Javierre, C.	2014	Research in Developmental Disabilities, 35(11):2624–2634.
Physical activity among adults with intellectual disabilities living in community settings.	Peterson, J. J., Janz, K. F., and Lowe, J. B.	2008	Preventive medicine, 47(1):101–106.
tellectual disability in children: Definition, diagnosis, and assessment of needs.	Pivalizza, P., Lalani, S., Firth, H. V., and Bridgemohan, D. C.	2018	
The physical activity patterns of adolescents with intellectual disabilities: A descriptive study	Queralt, A., Vicente-Ortiz, A., and Molina-García, J.	2016	Disability and Health Journal, 9(2):341–345.
Meta-analysis of the effect of exercise programs for individuals with intellectual disabilities.	Shin, I.-S. and Park, E.-Y.	2012	Research in Developmental Disabilities, 33(6):1937– 1947

Barriers, enjoyment, and preference for physical activity among adults with intellectual disability.	Temple, V. A.	2007	International Journal of Rehabilitation Research, 30(4):281–287.
Factors associated with high levels of physical activity among adults with intellectual disability.	Temple, V. A.	2009	International Journal of Rehabilitation Research, 32(1):89– 92.
Physical activity of adults with mental retardation: review and research needs.	Temple, V. A., Frey, G. C., and Stanish, H. I.	2006	American Journal of Health Promotion, 21(1):2– 12.
Game reward systems: Gaming experiences and social meanings.	Wang, H. and Sun, C.-T. (	2011	
Global health risks: mortality and burden of disease attributable to selected major risks.	World Health Organization	2009	
Recommendations for the Optimal Design of Exergame Interventions for Persons with Disabilities: Challenges, Best Practices, and Future Research.	Wiemeyer, J., Deutsch, J., Malone, L. A., Rowland, J. L., Swartz, M. C., Xiong, J., and Zhang, F. F.	2015	Games for Health Journal, 4(1):58–62.
ICD-10 Version:2016	World Health Organization	2016	International statistical classification of diseases and related health problems, chapter v; mental and behavioural disorders, (f00-f99).

B.2 AAC review

When deciding on what AAC symbol system to use, the following were investigated.

Symbol systems	**Usage, pros and cons (if applicable)**
Bliss Blissymbolics Communication International (2019)	Bliss is an international, graphical system. Words and concepts are represented by logical symbols instead of words. Mostly used by people with significant motor speech deficits. Can be used to express complex, grammatically correct sentences as well as just simple words and concepts. Seems too complex for this purpose, as we are only looking to supplement written communication, not substitute it completely.
WLS Widgit Software	Widgit Literacy Symbols (previously called Rufus) is a continuously growing set of symbols, containig more than 17000 simple, colorful symbols. Especially designed for written information and supports 17 languages and are used all over the world. Follows set rules of schematic structure. Unclear if there exists a way to access products for educational purposes, as a single installation starts at 189£.
PCS Ergostart	Picture communication systems, has around 3000 symbols with text description. Widespread use in many countries, also in Norway. It is used by Tobii Dynavox, who are making many different tools and aids for communication for people with disabilities, like the boardmaker Tobii Dynavox (2019) and specially designed tablets for text and speech. In Norway, the company providing PCS also can provide varying accessories and tools to use with the PCS symbols, like themed boards and animations.

SymbolStix n2y	Created by n2y, a company focusing on accessible learning for people with complex learning needs and autism. SymbolStix contains a large symbol database, with nearly 40000 symbols, and n2y are continously adding more symbols. n2y wants to provide relevant and age appropriate symbols for education, social and cultural purposes. Can be used in a simple form such as flashcards but there is also software which allows more complex storytelling where symbols are combined to create individual communication boards. SymbolStix PRIME does not seem to offer a student licence, and it is 87$ for a licence. However, there is a 30-day trial.

Appendix C

Research Ethics Documents and Approvals

C.1 Regional Committees for Medical and Health Research Ethics (REC)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			01.11.2016	2016/1770/REK nord
			Deres dato:	Deres referanse:
			20.09.2016	

Vår referanse må oppgis ved alle henvendelser

Audny Anke
Rehabiliteringsavdelinga

2016/1770 Fysisk aktivitet med e-helse støtte hos personer med utviklingshemning.

Forskningsansvarlig: Universitetssykehuset Nord Norge
Prosjektleder: Audny Anke

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 20.10.2016. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektleders prosjektomtale
Mennesker med psykisk utviklingshemning har dårligere helse enn den generelle befolkningen. Kun 9% når måltall om grad av fysisk aktivitet. Studier hvor en ønsker å oppnå økt fysisk aktivitet har ikke hatt signifikante effekter, og det er derfor behov for nye innovative metoder. Bruk av motiverende mobil e-helse støtte har ikke tidligere vært prøvd. Vi vil 1) kartlegge brukeres behov i en teoretisk modell ved bruk av fokus-gruppe intervju, og individuelle intervjuer, og ut fra dette utvikle et fleksibelt program for fysisk aktivitet ; 2) utvikle en motiverende e-helse støtte (app); og 3) undersøke effekten av et program for økt fysisk aktivitet med bruk av motiverende e-helse-støtte i en randomisert kontrollert studie. Kontrollgruppen får vanlig behandling. Primær-resultat er grad av fysisk aktivitet (målt med steps/day og et spørreskjema). Sekundære utfalls-mål er body mass index, blodtrykk, funksjonelle tester og psykososial funksjon.

Vurdering

Forskning på personer uten eller med redusert samtykkekompetanse
Forskning som inkluderer personer uten, eller med redusert samtykkekompetanse kan bare finne sted dersom eventuell risiko eller ulempe for personen er ubetydelig, personen selv ikke motsetter seg det, og det er grunn til å anta at resultatene av forskningen kan være til nytte for den aktuelle personen eller for andre personer med samme aldersspesifikke lidelse, sykdom skade eller tilstand. Det må heller ikke være grunn til å tro at personen ville motsatt seg deltakelse i forskningsprosjektet hvis vedkommende hadde hatt samtykkekompetanse. Det er også et krav at tilsvarende forskning ikke kan gjennomføres på personer med samtykkekompetanse, jf. helseforskningslovens § 18.

Utviklingshemmede er å anse som en sårbar gruppe, men det er likevel viktig at det forskes på denne gruppen. Det må stilles særlige krav til hvordan slike deltagere informeres om prosjektet for å forsikre om at de har forstått hva deltagelse innebærer. Prosjektleder har redegjort for hvordan rekruttering og inklusjon

Besøksadresse:
MH-bygget UiT Norges arktiske universitet 9037 Tromsø
REK nord
Telefon: 77646140
E-post: rek-nord@asp.uit.no
Web: http://helseforskning.etikkom.no/

skal finne sted, og komiteen anser dette som forsvarlig. I dette prosjektet ansees risiko eller ulempe for deltaker som liten, og det er grunn til å anta at resultatene av forskningen vil være til nytte for de aktuelle personene og gruppen.

Det står nevnt i søknaden at deltagere under 16 år også kan få mulighet til å delta, uten at dette er nærmere begrunnet. Komiteen legger til grunn at studien bare gjennomføre på voksne deltagere.

Oppbevaring av data
Det opplyses at koblingsnøkkel vil oppbevares på institusjonens server. Komiteen legger således til grunn at prosjektmedarbeidere som kun er tilknytte UIT og ikke UNN bare vil behandle avidentifiserte data.

Forespørsel/informasjonsskriv/samtykkeerklæring
I søknaden opplyses det at det skal utleveres helseinformasjon med Danmark-Danish Disability Sport Information Centre. Dette må det opplyses om i forespørselsskrivet, og det må også fremgå at det bare er avidentifiserte opplysninger som utleveres.

Vedtak

Med hjemmel i helseforskningsloven §§ 2 og10 godkjennes prosjektet.
Før prosjektet kan igangsettes må det sendes inn revidert informasjonsskriv i tråd med komiteens merknader.

Skrivet sendes som vedlegg i e-post til post@helseforskning.etikkom.no

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest 30.06.2023, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK nord dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

[redacted]
Sekretariatsleder

Kopi til: [redacted]

rek-svar@unn.no

Besøksadresse:
MH-bygget UiT Norges arktiske universitet
REK 9037 Tromsø

Telefon: 77646140
E-post: rek-nord@asp.uit.no
Web: http://helseforskning.etikkom.no/

C.2 Norwegian Centre for Research data approval

Meldeskjema - Meldinger

Referanse	**Status**
894552	Vurdert

NSD Personvern 08.03.2019 15:29

Det innsendte meldeskjemaet med referansekode 894552 er nå vurdert av NSD.

Følgende vurdering er gitt:

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 7.3.2019, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

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

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle særlige kategorier av personopplysninger om helse, samt alminnelige personopplysninger, frem til 31.12.2020. Deretter vil datamaterialet anonymiseres.

LOVLIG GRUNNLAG
Prosjektet vil behandle særlige kategorier av personopplysninger om utvalg 1 (unge voksne med lettere til moderat psykisk utviklingshemming) med grunnlag i at oppgaven er nødvendig for gå utføre en oppgave i allmennhetens interesse. For alminnelige og særlige kategorier av personopplysninger vil lovlig grunnlag for behandlingen være personvernforordningen art. 6 nr. 1 bokstav e), jf. nr. 3 bokstav b), jf. art. 9 nr. 2 bokstav j), jf. personopplysningsloven §§ 8 og 9. NSD vurderer at samfunnets interesse i at behandlingen foretas, klart overstiger ulemper for den enkelte. Vi viser til at utvalget gis tilpasset informasjon og deltar av egen fri vilje, og det innhentes supplerende samtykke fra pårørende som et ulempereduserende tiltak.

Prosjektet vil behandle alminnelige personopplysninger om utvalg 2 (fagpersoner og personer som jobber med/har relasjoner i brukergruppen) på bakgrunn av samtykke. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 a). NSD minner om at utvalget har taushetsplikt overfor pasienter, og at det er studentenes og informantenes felles ansvar å sørge for at taushetsplikten ikke brytes under intervjuet.

PERSONVERNPRINSIPPER NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen:
- om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen

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

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

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

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

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

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

UiT - Norges arktiske universitet og UNN - Universitetssykehuset Nord-Norge er felles behandlingsansvarlige institusjoner. NSD legger til grunn at behandlingen oppfyller kravene til felles behandlingsansvar, jf. personvernforordningen art. 26.

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

Lykke til med prosjektet!

Kontaktperson hos NSD: [redacted]
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

C.2.1 Information and approval letter sample 1

Vil du delta i forskningsprosjektet ”Spill-inspirert applikasjon for motivasjon til økt grad av fysisk aktivitet”?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å motivere til økt fysisk aktivitet blant personer med utviklingshemming. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet er en del av en masteroppgave i informatikk/datateknologi. Målet med prosjektet er å motivere personer med utviklingshemminger til å være mer fysisk aktive. Får å oppnå dette målet har det blitt laget flere prototyper av spill. Din deltakelse vil gå ut på å teste et eller flere spill, slik at vi kan kartlegge i hvilken grad det bidrar til å motivere deg til å være mer fysisk aktiv.

Hvem er ansvarlig for forskningsprosjektet?
Prosjektet er en del av en masteroppgave skrevet ved NTNU (Norges teknisk-naturvitenskapelige universitet). Prosjektet utføres av Ingrid Evensen, Ida Wold og Jens Brandsgård Omfjord. Veiledere på prosjektet er Letizia Jaccheri og Javier Gomez Escribano.

Hva innebærer det for deg å delta?

Om du velger å delta, vil du bli med på et utvalg av følgende aktiviteter for datainnsamling:

- Et innledende intervju for å kartlegge din nåværende daglige fysiske aktivitet.
- Delta i et eksperiment der du prøve et spill i en kort periode på et par timer.
- Delta i et eksperiment der du tar i bruk spillet i 3-7 dager. Du vil bruke spillet så mye du selv synes er naturlig.
- Til slutt vil du få et nytt spørreskjema slik at du kan dele dine erfaringer med oss.
- Intervju om dine opplevelser og tanker om spillet.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Det vil bare være studentene og veilederne, nevnt tidligere, som har tilgang til opplysningene.

Navn og kontaktopplysninger om deg vil bli erstattet med en kode som lagres på en egen navneliste adskilt fra øvrige data.

Deltakere vil ikke kunne gjenkjennes i publikasjon.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Prosjektet skal etter planen avsluttes 31.12.2019, og etter dette vil datamaterialet bli anonymisert.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra NTNU har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- NTNU - Norges teknisk-naturvitenskapelige universitet ved Letizia Jaccheri på epost (letizia.jaccheri@ntnu.no) eller telefon: 73 59 34 69
- NTNU - Norges teknisk-naturvitenskapelige universitet ved Ingrid Evensen på epost (ingriev@stud.ntnu.no)
- NTNU - Norges teknisk-naturvitenskapelige universitet ved Ida Wold på epost (idawol@stud.ntnu.no)
- NTNU - Norges teknisk-naturvitenskapelige universitet ved Jens B. Omfjord på epost (jensbom@stud.ntnu.no)
- Vårt personvernombud: Thomas Helgesen på thomas.helgesen@ntnu.no
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Letizia Jaccheri	Ingrid Evensen, Ida Wold, Jens B. Omfjord
Prosjektansvarlig (Forsker/veileder)	Prosjektdeltaker (Studenter)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *"Spill-inspirert applikasjon for motivasjon til økt grad av fysisk aktivitet"*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ å delta i innledende intervju
- ☐ å delta i eksperiment for testing av spill
- ☐ å svare på avsluttende spørreskjema
- ☐ å delta i avsluttede intervju
- ☐ at foresatt eller støtteperson kan gi opplysninger om meg til prosjektet

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. *31.12.2019*

(Signert av prosjektdeltaker, dato)

C.2.2 Information and approval letter sample 2

Vil du delta i forskningsprosjektet ”Spill-inspirert applikasjon for motivasjon til økt grad av fysisk aktivitet”?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å motivere til økt fysisk aktivitet blant personer med utviklingshemming. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet er en del av en masteroppgave i informatikk/datateknologi. Målet med prosjektet er å motivere personer med utviklingshemminger til å være mer fysisk aktive. Får å oppnå dette målet har det blitt laget flere prototyper av spill. Din deltakelse i prosjektet vil bidra til å forme et eller flere spill som utvikles i prosjektet.

Hvem er ansvarlig for forskningsprosjektet?
Prosjektet er en del av en masteroppgave skrevet ved NTNU (Norges teknisk-naturvitenskapelige universitet). Prosjektet utføres av Ingrid Evensen, Ida Wold og Jens Brandsgård Omfjord. Veiledere på prosjektet er Letizia Jaccheri og Javier Gomez Escribano.

Hva innebærer det for deg å delta?

Om du velger å delta, vil du bli med på følgende:

- Et intervju for hente inn informasjon om domenet og tilbakemeldinger til prototypen av spillet
    - Eventuelt senere intervjuer om ønskelig fra begge parter

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Det vil bare være studentene og veilederne, nevnt tidligere, som har tilgang til opplysningene.

Navn og kontaktopplysninger om deg vil bli erstattet med en kode som lagres på en egen navneliste adskilt fra øvrige data.

Deltakere vil ikke kunne gjenkjennes i publikasjon, med mindre samtykke for dette gis i samtykkeerklæringen (nederst i dette dokumentet).

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Prosjektet skal etter planen avsluttes 31.12.2019, og etter dette vil datamaterialet bli anonymisert.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra NTNU har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- NTNU - Norges teknisk-naturvitenskapelige universitet ved Letizia Jaccheri på epost (letizia.jaccheri@ntnu.no) eller telefon: 73 59 34 69
- NTNU - Norges teknisk-naturvitenskapelige universitet ved Ingrid Evensen på epost (ingriev@stud.ntnu.no)
- NTNU - Norges teknisk-naturvitenskapelige universitet ved Ida Wold på epost (idawol@stud.ntnu.no)
- NTNU - Norges teknisk-naturvitenskapelige universitet ved Jens B. Omfjord på epost (jensbom@stud.ntnu.no)
- Vårt personvernombud: Thomas Helgesen på thomas.helgesen@ntnu.no
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Letizia Jaccheri	Ingrid Evensen, Ida Wold, Jens B. Omfjord
Prosjektansvarlig (Forsker/veileder) Svar på spørsmålene under ved å	Prosjektdeltaker (Studenter)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *"Spill-inspirert applikasjon for motivasjon til økt grad av fysisk aktivitet"*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ å delta i ustrukturert intervju
- ☐ at opplysninger om meg publiseres slik at jeg kan gjenkjennes, for å begrunne valgene som er gjort på bakgrunn av intervju(ene).

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. *31.12.2019*

(Signert av prosjektdeltaker, dato)

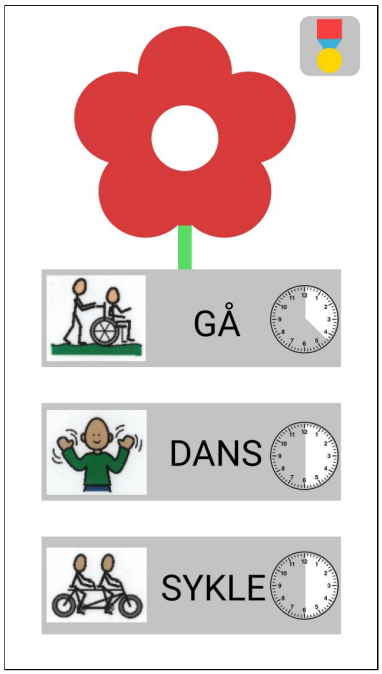
C.2.3 Adapted information and approval letter

Vil du delta i forskning?

Forskningen handler om fysisk aktivitet og spill.

Mål:

Motivere til mer daglig fysisk aktivitet
Teste en mobilapplikasjon



Du må:

Være 16-35 år
Ha en utviklingshemming
Kunne gå uten hjelp

Du vil være med på:

Lære å bruke spillet
Prøve spillet selv
En ledsager er også med
Si din mening om spillet

Dine rettigheter:

Du bestemmer selv om du vil være med
Du kan slutte når du vil
Du kan få se informasjonen om deg selv
Informasjonen blir ikke lagret med ditt navn

Data som blir samlet inn:

Hva du gjør når du spiller
Det du sier om spillet
Foreldre eller ledsagere deler informasjon om meg til prosjektet

Kontakter:

Masterstudenter fra NTNU
Ingrid Evensen: ingriev@stud.ntnu.no
Jens B. Omfjord: jensbom@stud.ntnu.no

Prosjektansvarlig
Letizia Jaccheri: letizia.jaccheri@ntnu.no

Underskrift

_____

Deltager, dato

C.2.4 Interview guide sample 1

Intervjuguide

Til dette utvalget er det satt opp to forskjellige intervjuguider. Disse vil bli gjennomført separat fra hverandre. Personer i dette utvalget kan være med på enten et av intervjuene eller begge.

Intervju 1

Ustrukturerte intervjuer med eller uten støtteperson(er) og/eller foresatte rundt temaene

- Fysisk aktivitet, daglig nivå av aktivitet, hvilke aktiviteter?
    - Trening
    - Jobb
    - Fritid
- Eventuelle fysiske begrensninger
- Motivasjon til trening og aktivitet
- Daglige rutiner, hvordan ser en hverdag ut? en helg?
- Kjennskap til andre mobilspill/applikasjoner
    - Applikasjoner for trening

Intervju 2

Ustrukturert intervjuer i samarbeid med støtteperson(er) og/eller foresatte rundt hva brukeren mener om følgende temaer:

- Den generelle opplevelsen av å spille spillet
- De sosiale forholdene i spillet inkludert samarbeid og sosial samhandling med andre utviklingshemmede, ledsagere og familie
- Spillets motivasjon til trening og hvordan den kan passe inn i deres hverdagen
- Brukervennlig av spillet
    - Hvordan informasjon blir formidlet
    - “Kulhetsfaktoren” til spillet
- Hvordan utendørs navigeringen i spillet oppleves
- Hvilken målgruppe passer spillet til, spesielt hvilke grader av utviklingshemming

C.2.5 Interview guide sample 2

Intervjuguide

Til dette utvalget er det satt opp to forskjellige intervjuguider. Disse vil bli gjennomført separat fra hverandre. Personer i dette utvalget kan være med på enten et av intervjuene eller begge.

Intervju 1

Ustrukturerte intervjuer med eksperter rundt temaene

- Mobilutvikling
- Applikasjonsutvikling
- Spillutvikling
- Ønske om direkte tilbakemelding på prototype
    - Bruk av farger/design
    - Layout
    - Flyt i spillet
    - Belønningssystemet
    - Eventuelt

Intervju 2

Ustrukturerte intervjuer av eksperter rundt temaene i forhold til prototypen

- Tanker om spillet i sin helhet
- Brukervennlig av spillet
    - hvordan informasjon blir formidlet
    - fargevalg og kontraster
    - knapper og flyten i spillet
- Motivasjonen til fysisk aktivitet i spillet og hvordan spillet kan brukes i utviklingshemmedes hverdag
- Hvordan utendørs navigering i spillet vil oppleves
- De sosiale forholdene i spillet inkludert samarbeid og sosial samhandling med andre utviklingshemmede, ledsagere og familie

C.2.6 Questionnaire

Spørsmål til brukervennligheten av spillet

Svar på spørsmålene under.
Sette kryss for hver påstand.

	Uenig	Ikke enig eller uenig	Enig
Jeg vil bruke spillet ofte.			
Spillet er vanskelig.			
Spillet er enkelt.			
Jeg trenger hjelp for å bruke spillet.			
Spillet henger bra sammen			
De ulike delene er forskjellige.			
Mine venner vil lære seg spillet raskt.			
Spillet er tungvint å bruke.			
Jeg klarte å bruke spillet.			
Jeg måtte lære meg mange andre ting først.			

Har du andre tilbakemeldinger.

De kan du skrive her:

Bibliography

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Antener, G., Bolfing, A., and Calabrese, S. (2014). Easy to surf - what makes websites accessible to people with intellectual and learning disabilities. In Miesenberger, K., Fels, D., Archambault, D., Peňáz, P., and Zagler, W., editors, *Computers Helping People with Special Needs*, pages 157–160, Cham. Springer International Publishing.

Apple (2019). Apple health . a bold way to look at your health. https://www.apple.com/ios/health/, checked 2019-05-29.

Apple (2019). itunes app store, health fitness, popular apps. https://itunes.apple.com/no/genre/ios-health-fitness/id6013?mt=8, checked 2019-05-29.

Axelsson, O. and Carlström, F. (2016). Evaluation targeting react native in comparison to native mobile development.

Azumio (2019). Argus: Quantify your day-to-day. https://www.azumio.com/s/argus/index.html, checked 2019-05-29.

Badia, M., Orgaz, B. M., Verdugo, M. A., Ullán, A. M., and Martínez, M. M. (2011). Personal factors and perceived barriers to participation in leisure activities for young and adults with developmental disabilities. *Research in Developmental Disabilities*, 32(6):2055–2063.

Blissymbolics Communication International (2019). - about blissymbolics. http://www.blissymbolics.org/, checked 2019-05-29.

Bodde, A. E. and Seo, D.-C. (2009). A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disability and Health Journal*, 2(2):57–66.

Bossink, L., van der Putten, A. A., and Vlaskamp, C. (2017). Understanding low levels of physical activity in people with intellectual disabilities: A systematic review to identify barriers and facilitators. *Research in Developmental Disabilities*, 68:95–110.

Brooke, J. et al. (1996). Sus-a quick and dirty usability scale. *Usability evaluation in industry*, 189(194):4–7.

Cadmus-Bertram, L. A., Marcus, B. H., Patterson, R. E., Parker, B. A., and Morey, B. L. (2015). Randomized trial of a fitbit-based physical activity intervention for women. *American journal of preventive medicine*, 49(3):414–418.

Cambridge Dictionary (2018). Definition of gamification in english. https://dictionary.cambridge.org/us/dictionary/english/gamification, checked 2019-05-29.

Case, M. A., Burwick, H. A., Volpp, K. G., and Patel, M. S. (2015). Accuracy of smartphone applications and wearable devices for tracking physical activity data. *Jama*, 313(6):625–626.

Communication Matters (ISAAC UK). What is aac? https://www.communicationmatters.org.uk/page/what-is-aac, checked 2019-05-29.

Cooper, S.-A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., and Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice*, 16(1):110.

Crookall, D. (2010). Serious games, debriefing, and simulation/gaming as a discipline. *Simulation & gaming*, 41(6):898–920.

Dairo, Y. M., Collett, J., Dawes, H., and Oskrochi, G. R. (2016). Physical activity levels in adults with intellectual disabilities: A systematic review. *Preventive medicine reports*, 4:209–219.

Diaz, K. M., Krupka, D. J., Chang, M. J., Peacock, J., Ma, Y., Goldsmith, J., Schwartz, J. E., and Davidson, K. W. (2015). Fitbit®: An accurate and reliable device for wireless physical activity tracking. *International journal of cardiology*, 185:138–140.

Edler, C. and Rath, M. (2014). People with learning disabilities using the ipad as a communication tool-conditions and impact with regard to e-inclusion. In *International Conference on Computers for Handicapped Persons*, pages 177–180. Springer.

El-Amrawy, F. and Nounou, M. I. (2015). Are currently available wearable devices for activity tracking and heart rate monitoring accurate, precise, and medically beneficial? *Healthcare informatics research*, 21(4):315–320.

Elsevier (2018). Sciencedirect. https://www.sciencedirect.com/, visited 2018-10-10.

Ergostart. Picture communication systems (pcs). https://www.ergostart.no/picture-communication-systems-pcs, checked 2019-05-29.

Figma. Figma. https://www.figma.com/, checked 2019-05-29.

Furuskog, M. and Wemyss, S. (2016). Cross-platform development of smartphone applications: An evaluation of react native.

George, J., Dietzsch, N., Bier, M., Zirpel, H., Perl, A., and Robra-Bissantz, S. (2014). Testing the perceived ease of use in social media. In *International Conference on Computers for Handicapped Persons*, pages 169–176. Springer.

Google (2018). Google scholar. https://scholar.google.no/, visited 2018-10-11.

Google (2019a). Google fit. https://www.google.com/fit/, checked 2019-05-29.

Google (2019b). Google play, activity tracker apps. https://play.google.com/store/search?q=activity%20tracker&c=apps, checked 2019-05-29.

Hamilton, S., Hankey, C. R., Miller, S., Boyle, S., and Melville, C. A. (2007). A review of weight loss interventions for adults with intellectual disabilities. *Obesity Reviews*, 8(4):339–345.

Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., and Strydom, A. (2010). Major Health Risks in Aging Persons With Intellectual Disabilities: An Overview of Recent Studies. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1):59–69.

Haveman, M., Perry, J., Salvador-Carulla, L., Walsh, P. N., Kerr, M., de Valk, H. V. S. L., Hove, G. V., Berger, D. M., Azema, B., Buono, S., Cara, A. C., Germanavicius, A., Linehan, C., Määttä, T., Tossebro, J., and Weber, G. (2011). Ageing and health status in adults with intellectual disabilities: Results of the european pomona ii study. *Journal of Intellectual & Developmental Disability*, 36(1):49–60.

Helsedirektoratet. https://helsedirektoratet.no/folkehelse/fysisk-aktivitet/anbefalinger-fysisk-aktivitet, visited 2018-09-03.

Hersh, M. (2014). Evaluation framework for ict-based learning technologies for disabled people. *Computers & Education*, 78:30–47.

Hilgenkamp, T. I., Reis, D., van Wijck, R., and Evenhuis, H. M. (2012). Physical activity levels in older adults with intellectual disabilities are extremely low. *Research in Developmental Disabilities*, 33(2):477–483.

IEEE (2018). Ieee xplore. https://ieeexplore.ieee.org/Xplore/home.jsp, visited 2018-09-03.

Inclusion Europe (2019). European standards for making information easy to read and

understand. https://easy-to-read.eu/european-standards/, checked 2019-05-29.

isaac Norge (2019). Tegnsystemer i ask - grafiske tegnsystemer. http://www.isaac.no/fagstoff/tegnsystemer-i-ask/grafiske-tegnsystemer/, checked 2019-05-29.

ITO Technologies (2019). Pedometer (at google play). https://play.google.com/store/apps/details?id=com.tayu.tau.pedometer&hl=en_US, checked 2019-05-29.

Kontio, J., Lehtola, L., and Bragge, J. (2004). Using the focus group method in software engineering: Obtaining practitioner and user experiences. pages 271– 280.

Krueger, R. A. and Casey, M. A. (2000). *Focus groups: a practical guide for applied research*. Sage Publications, Thousand Oaks, Calif, 3rd ed edition.

Kuijken, N. M. J., Naaldenberg, J., Nijhuis-van der Sanden, M. W., and van Schrojenstein-Lantman de Valk, H. M. J. (2015). Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives: Perspectives of people with ID on healthy living. *Journal of Intellectual Disability Research*, 60(3):228–241.

Kuru, H. (2018). Behavior change techniques used in mobile applications targeting physical activity: A systematic review. *Current and Emerging mHealth Technologies: Adoption, Implementation, and Use*, pages 23–35.

Laabidi, M., Jemni, M., Jemni Ben Ayed, L., Ben Brahim, H., and Ben Jemaa, A. (2014). Learning technologies for people with disabilities. *Journal of King Saud University - Computer and Information Sciences*, 26(1):29–45.

Lorentzen, E. (2008). Psykisk utviklingshemning - hvordan stilles diagnosen? *Tidsskrift for Den norske legeforening*, 128(2):201–202.

March, S. T. and Smith, G. F. (1995). Design and natural science research on information technology. *Decision Support Systems*, 15(4):251 – 266.

Melville, C. A., Mitchell, F., Stalker, K., Matthews, L., McConnachie, A., Murray, H. M., Melling, C., and Mutrie, N. (2015). Effectiveness of a walking programme to support adults with intellectual disabilities to increase physical activity: walk well cluster-randomised controlled trial. *International Journal of Behavioral Nutrition and Physical Activity*, 12(1):125.

Miesenberger, K. and Petz, A. (2014). " easy-to-read on the web": State of the art and needed research. In *International Conference on Computers for Handicapped Persons*, pages 161–168. Springer.

n2y. Symbolstix prime. https://www.n2y.com/symbolstix-prime/, checked 2019-05-29.

NFU (2019). Informasjon for alle. http://www.nfunorge.org/Om-utviklingshemning/Lettlest/?fbclid=IwAR212fexCizVY94GZ9ilJ66UyVRYp_Q8HEFUYCOmzkHnS2Crl3guLCe1Lx0, checked 2019-05-29.

NSD (2019). Frequently asked questions. https://nsd.no/personvernombud/en/help/faq.html, checked 2019-05-29.

Oates, B. J. (2006). *Researching Information Systems and Computing*. Sage Publications Ltd.

Oh, Y. and Yang, S. (2010). Defining exergames & exergaming. *Proceedings of Meaningful Play*, pages 1–17.

Oviedo, G. R., Guerra-Balic, M., Baynard, T., and Javierre, C. (2014). Effects of aerobic, resistance and balance training in adults with intellectual disabilities. *Research in Developmental Disabilities*, 35(11):2624–2634.

Peterson, J. J., Janz, K. F., and Lowe, J. B. (2008). Physical activity among adults with intellectual disabilities living in community settings. *Preventive medicine*, 47(1):101–106.

Pivalizza, P., Lalani, S., Firth, H. V., and Bridgemohan, D. C. (2018). Intellectual disability in children: Definition, diagnosis, and assessment of needs. *UpToDate [en línea][consultado el 21/02/2018]. Disponible en www. uptodate. com/contents/inte llectual-disability-in-children-definition-diagno sis-and-assessment-of-needs*.

Queralt, A., Vicente-Ortiz, A., and Molina-García, J. (2016). The physical activity patterns of adolescents with intellectual disabilities: A descriptive study. *Disability and Health Journal*, 9(2):341–345.

Shin, I.-S. and Park, E.-Y. (2012). Meta-analysis of the effect of exercise programs for individuals with intellectual disabilities. *Research in Developmental Disabilities*, 33(6):1937–1947.

Temple, V. A. (2007). Barriers, enjoyment, and preference for physical activity among adults with intellectual disability. *International Journal of Rehabilitation Research*, 30(4):281–287.

Temple, V. A. (2009). Factors associated with high levels of physical activity among adults with intellectual disability. *International Journal of Rehabilitation Research*, 32(1):89–92.

Temple, V. A., Frey, G. C., and Stanish, H. I. (2006). Physical activity of adults with mental retardation: review and research needs. *American Journal of Health Promotion*, 21(1):2–12.

Tobii Dynavox. https://www.tobiidynavox.no/, checked 2019-05-29.

Tobii Dynavox (2019). Boardmaker. https://www.tobiidynavox.com/software/windows-software/boardmaker-app/?redirect=true, checked 2019-05-29.

W3C (2018a). About w3c. https://www.w3.org/Consortium/, checked 2019-05-29.

W3C (2018b). Introduction to web accessibility. https://www.w3.org/WAI/fundamentals/accessibility-intro/, checked 2019-05-29.

Wang, H. and Sun, C.-T. (2011). Game reward systems: Gaming experiences and social meanings. In *DiGRA Conference*.

Web Accessibility in Mind (WebAIM) (2019). Color contrast checker. https://webaim.org/resources/contrastchecker/, checked 2019-05-29.

WHO, W. H. O. (2009). *Global health risks: mortality and burden of disease attributable to selected major risks*. Geneva: World Health Organization.

Widgit Software. About widgitsymbol users: Who uses symbols. https://www.widgit.com/index.php, checked 2019-05-29.

Wiemeyer, J., Deutsch, J., Malone, L. A., Rowland, J. L., Swartz, M. C., Xiong, J., and Zhang, F. F. (2015). Recommendations for the Optimal Design of Exergame Interventions for Persons with Disabilities: Challenges, Best Practices, and Future Research. *Games for Health Journal*, 4(1):58–62.

Wilkinson, P. (2016). A brief history of serious games. In *Entertainment computing and serious games*, pages 17–41. Springer.

World Health Organization. http://www.who.int/dietphysicalactivity/factsheet_adults/en/, visited 2018-09-03.

World Health Organization (2016). International statistical classification of diseases and related health problems, chapter v; mental and behavioural disorders, (f00-f99).

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