UiT The Arctic University of Norway

Kunstig intelligens, digital helse og helseteknologi – etiske implikasjoner for medisinsk og helsefaglig forskning

Professor Gunnar Hartvigsen

Forskningsgruppen for helseinformatikk og helseteknologi
Institutt for informatikk
Fakultet for naturvitenskap og teknologi
Universitetet i Tromsø – Norges arktiske universitet

Helgelandssykehuset HF

Hvem er jeg?

- MSc & Ph.D., informatikk (AI), Universitetet i Tromsø – Norges arktiske universitet (UiT)
- Professor i informatikk (1994-)
- Medisinsk informatikk og telemedisin (1998 -)
- Instituttleder, Institutt for informatikk, UiT (1996-2001)
- Prodekan, Mat.nat. fak., UiT (2005-2009)
- Professor II, Nasjonalt senter for telemedisin (NST), Universitetssykehuset Nord-Norge (UNN) (2000-2015)
- Professor II, Nasjonalt senter for e-helseforskning, UNN (2016-2017)
- Senterleder, Tromsø Telemedicine Laboratory, UNN (2007-2015) (Senter for forskningsdrevet innovasjon)
- NENT - Nasjonal forskningsetisk komite for naturvitenskap og teknologi, 2010–2013, 2014–2017
- Professor II, Institutt for helse og sykepleievit., Universitetet i Agder (2018-2022)
- Professor II, Helgelandssykehuset (2023-)
- Utenlandsopphold: Univ. av Twente, Nederland; TU München, Tyskland; UC Davis, California, USA; TU Valencia, Spania; Karolinska Institutet, Sverige

MER INFO: **https://uit.no/ansatte/gunnar.hartvigsen**

KRONIKKER

Hartvigsen, G. Forskningsetikk – et lederansvar. *Forskningsetikk*, mars 2011, nr. 01, 11. Årgang, side 26.

Hartvigsen, G. Plagiering – det dummeste du kan gjøre som forsker? *Forskningsetikk*, nr. 2–3 (oktober), 2012, årgang 12, side 26

Hartvigsen, G. Kan publikasjonspoeng skape etiske dilemmas? *Forskningsetikk*, nr. 4 (November), 2012 årgang 12, side 22.

Hartvigsen, G. Rekk opp hånden alle som kjenner til forskningsetiske retningslinjer. *Forskningsetikk*, nr. 3 (Oktober), 2013 årgang 13, side 22.

Hartvigsen, G. Forskningens samfunnsansvar – gjelder det meg også? *Forskningsetikk*, nr. 3 (oktober), 2015 årgang 15, side 31.

Hartvigsen, G. Forskningsetikkens ti bud. Kronikk, Forskerforum, 6/2016 (årgang 48), s. 36–37.

Hartvigsen, G. Grenseløs teknologi (om farlig forskning). *Avisa Nordland,* side 3, 20.09.2016. (Kronikk i spalten "Nordlands Trompet")

Grenseløs teknologi

Nordlands Trompet

GUNNAR HARTVIGSEN

professor, UiT - Norges arktiske universitet

Marge framståande forskarar, deriblant professor Stephen Hawking ved Cambridge University, ytrar i 2014 bekymring om å advare mot at forskinga innan kunstig intelligens i verste fall vil føre til menneskeheitas undergang.

Mange framståande forskere har advart mot kunstig intelligens.

Research Ethics in Health Informatics – Why Bother?

Gunnar Hartvigsen*

**Department of Computer Science, University of Tromsø – The Arctic University of Norway, Tromsø, Norway*

Abstract

Research ethics is an obvious part of every researcher's life. For some areas like health informatics, the multi- and interdisciplinarity of the field make it necessary to pay attention to ethical guidelines, acts/laws, and principles from medicine, health science, science, technology, social sciences and humanities.

If you know where to look and what to look for, it is easy to find relevant information about research ethics. However, studies have indicated that we cannot take this knowledge for granted. If you do clinical trials in Norway, you have to apply to the Regional Committees for Medical and Health Research Ethics (REC) for approval. If you do studies with patients that do not imply any treatment or improvement of medical procedures, i.e., are not covered by the Health Research Act, you need to contact the "personvernombudet" (patient data protection ombudsman) to get approval for involving patients in your study. But for many research projects in health informatics, these kinds of approvals are not necessary. Some PhD students take part in large project with an existing approval by REC. This means that they probably have not been involved in writing the research protocol and applying for REC approval. As a consequence, the do not know this process very well nor the implications of this process.

For most researchers, ethical guidelines are not something they have good knowledge of. A small inquiry among PhD students in science and technology at the University of Tromsø – The Arctic University of Norway showed that ethical guidelines were vaguely known. This paper gives an overview of what kind of ethical guidelines, acts and ethical principles a researcher in a multi- and interdisciplinary field as health informatics needs to know and pay attention to. Norwegian laws and regulations are used to illustrate what kind of information that is needed.

Keywords:

Ethical guidelines, research ethics, health informatics

Introduction

Health Informatics is *"the interdisciplinary study of the design, development, adoption and application of IT-based innovations in healthcare services delivery, management and planning"* [1]. The multi- and interdisciplinarity of health informatics implies that a range of research methods and approaches might need to be applied in order to solve the research problems addressed, which again makes it necessary to pay attention to ethical guidelines, acts/laws, and principles from both medicine and health science, science and technology, and social sciences and humanities.

Researchers in health informatics often have their education and research training from one of these disciplines. E.g., researchers with a background in computer science often lack formal training in medicine, health science, social science and humanities, researchers in medicine are not familiar with experimental research in computer science and technology, etc. Compliance with ethical guidelines for research is an obvious part of doing research in a field. Also, for ethical guidelines, there are differences between the fields. And, as for research training, ethical guidelines vary a lot between different fields. If you do research in, e.g., computer science, it is sufficient to know the content of and follow ethical guidelines for science and technology. The same goes for other disciplines - researchers in that particular area have to adhere to the guidelines for that specific area. But, as indicated above, researchers in health informatics often have to deal with ethical guidelines and principles from many areas.

For many researchers, it is a challenge to know the ethical guidelines for a single area. A few years ago, Hartvigsen [2] conducted a survey among doctoral students at the Faculty of Science and Technology, University of Tromsø – The Arctic University of Norway (UiT). In this study, PhD students where asked whether they knew about ethical guidelines, and if they did, if they could name one of the guidelines. The result was rather discouraging; no one passed the test – the knowledge of research ethics was almost non-existing. The only positive result was that all respondents thought research ethics was important for their research.

But it is perhaps not surprising that Norwegian doctoral students fail to reproduce one of the guidelines: the document that presents the current ethical guidelines in science and technology spans nearly 20 pages [3]. Each of the 24 guidelines is presented with a detailed explanation. Similarly, ethical guidelines for social sciences, humanities, law and theology, consist of 47 different guidelines described in a 46-page document [4]. (Both sets of guidelines will be revised in 2016, but the length will be approximately the same.) These guidelines cover all relevant aspects of research ethics that a

Forskningsetikk er en selvsagt del av enhver forskers liv. For noen områder som helseinformatikk gjør fagets fler- og tverrfaglighet det nødvendig å ta hensyn til etiske retningslinjer, lover/lover og prinsipper fra medisin, helsevitenskap, naturvitenskap, teknologi, samfunnsvitenskap og humaniora.

Hartvigsen, G., Research Ethics in Health Informatics – Why Bother? I: Karlsson, D., et al. (Red.). SHI 2016. Proceedings of the 14th Scandinavian Conference on Health Informatics. (6–7. april, 2016, Gøteborg, Sverige). Linköping Electronic Conference Proceedings, No. 122. Linköping, Sweden: Linköping University Electronic Press, 2016, pp. 63–69.

Hartvigsen, G. Why guidelines for research ethics in science and technology should consider irreparable research, and why they don't. In: Ferri, F., Dwyer, N., Raicevich, S., Grifoni, P., Altiok, H., Andersen, H.T., Laouris, Y., Silvestri, C. (Eds.), Responsible Research and Innovation Actions in Science Education, Gender and Ethics: Cases and Experiences. SpringerBriefs in Research and Innovation Governance series, Springer, Vol. 1 (2018), side 87-94. (ISSN: 2452-0519 ISBN: 978-3-319-73206-0)

Chapter 11
Why Guidelines for Research Ethics in Science and Technology Should Consider Irreparable Research, and Why They Don't

Gunnar Hartvigsen

Abstract Science is about taking risks, discovering the unknown, and in the end making ground for new artefacts that contribute to the development of our society. But is this ideal really possible when within few years many research project will have the potential of the extermination of mankind? Many countries, including Norway, have their own guidelines for research ethics in science and technology. Unfortunately, the potential of irreparable research and thus unintended extermination of mankind is not an issue in existing guidelines for research ethics or in the public discussion of what kind of research we, as a global society, should accept and/or conduct. The society should have the possibility to be kept informed about potential irreparable research projects, examine them, and take the necessary actions to eliminate or minimize the risk or even terminate a project when this is the conclusion of the examination.

11.1 Introduction

The goal of this research is to discover new knowledge. In experimental science and technology, the results follow from controlled experiments. An essential part of experimental research is planning and control. The more advanced and risky the project is the greater need for planning and control. In short, we might say that science is concerned with taking risks and uncovering the unknown. The ultimate goal of experimental science should be to make ground for new artefacts that contribute to the development of our society. This should be the ideal for every research project.

Unfortunately, we have no ultimate guarantee that the outcome of a research project is in accordance with such an ideal. For some research areas, the results

G. Hartvigsen (✉)
Norwegian Committee for Research Ethics in Science and Technology (NENT), University of Tromsø – The Arctic University of Norway, Tromsø, Norway
e-mail: gunnar.hartvigsen@uit.no

F. Ferri et al., *Responsible Research and Innovation Actions in Science Education, Gender and Ethics*, SpringerBriefs in Research and Innovation Governance,

Vitenskap handler om å ta risiko, oppdage det ukjente, og til slutt lage plass til nye gjenstander som bidrar til utviklingen av samfunnet vårt. Men er dette idealet virkelig mulig når mange forskningsprosjekter innen få år vil ha potensial for utryddelse av menneskeheten?

Mange land, inkludert Norge, har egne forskningsetiske retningslinjer for naturvitenskap og teknologi. Potensialet for uopprettelig forskning og dermed utilsiktet utryddelse av menneskeheten er dessverre ikke et tema i eksisterende forskningsetiske retningslinjer eller i den offentlige diskusjonen om hva slags forskning vi som globalt samfunn bør akseptere og/eller utføre.

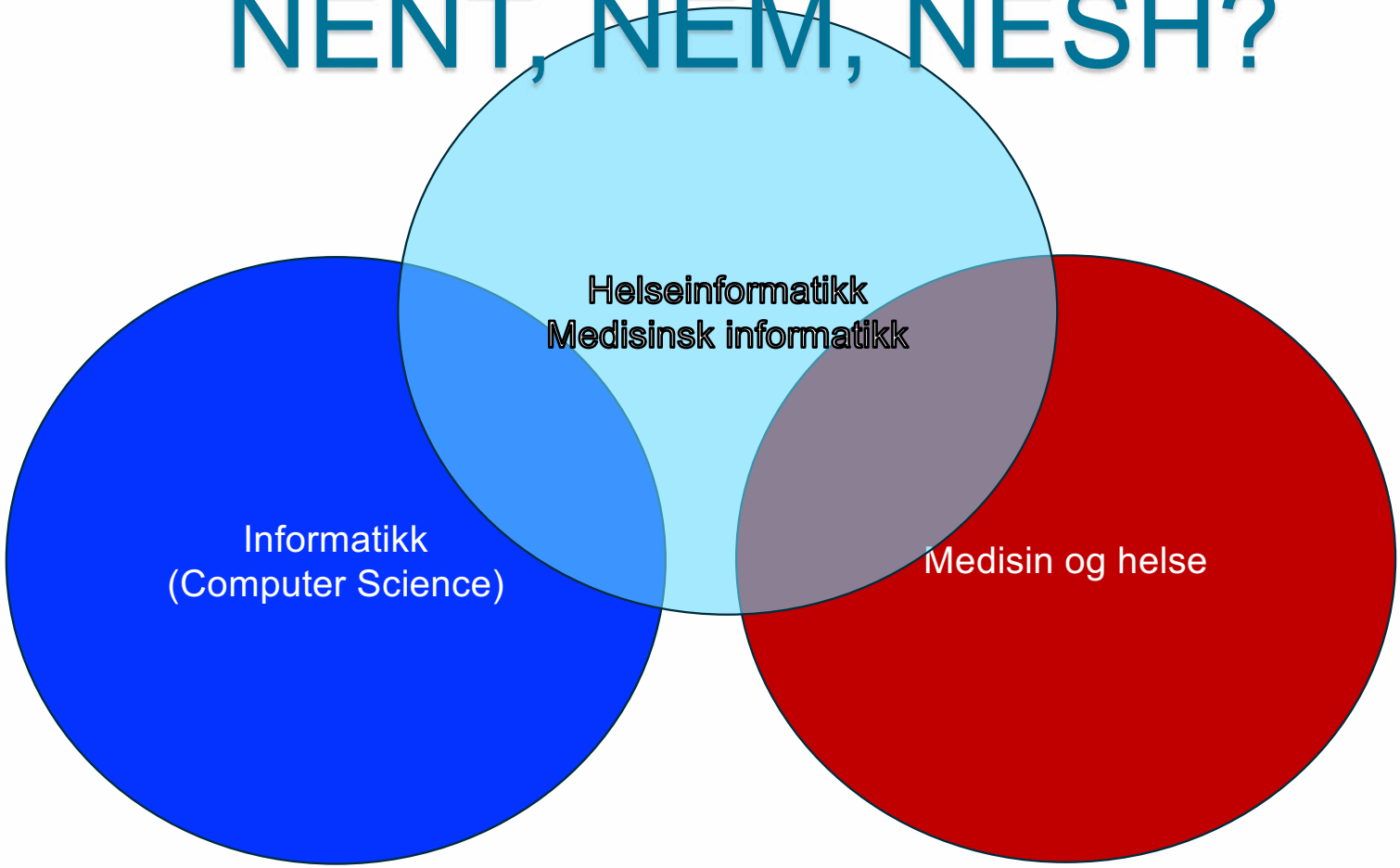
Samfunnet bør ha mulighet til å holdes informert om potensielle uopprettelige forskningsprosjekter, undersøke dem og iverksette nødvendige tiltak for å eliminere eller minimere risikoen eller til og med avslutte et prosjekt når dette er konklusjon av undersøkelsen.


Tromsø – Norges hovedstad
for (forskning på)
IKT i helse(sektoren)

TVERRFAGLIGE OG INTERNASJONALE PROSJEKTER: HVOR FOREGÅR FORSKNINGEN? HVILKE FORSKNINGSETISKE RETNINGSLINJER SKAL BENYTTES?


Hva er forskjellen mellom
forskning innen
informatikk, medisin og
helseinformatikk?

NENT, NEM, NESH?



KUN FOR

Fakultet for helse- og idrettsvitenskap

- Fakultet for helse- og idrettsvitenskap
- Fakultet for humaniora og pedagogikk
- Fakultet for kunstfag
- Fakultet for samfunnsvitenskap
- Fakultet for teknologi og realfag
- Handelshøyskolen ved UiA

Vi benytter (ofte) ulike typer personlige helse-sensorer

OURA


ŌURA
HURRY, ORDER NOW TO GET YOUR OURA RING IN 3–4 WEEKS.
THE EARLIER YOU ORDER, THE SOONER YOU'LL START WORKING
ON BETTER DAYS.
Great days start with good sleep


11:21
Søk
Sep
Tue, 26 Sep
Low
Medium
High
Goal progress
932 / 450 Cal
Total burn
3 296 Cal
Walking equivalency
16,5 km
Steps
21 218
Activity Score
93
Optimal
Activity contributors
Stay active
8h 22m inactivity
Move every hour
3 alerts
Meet daily goals
Optimal
Training frequency
Optimal
Training volume
Optimal
Recovery time
Optimal
Home
Sleep
Activity


75
Readiness contributors


Details
5:56
97
Good


ŌURA
205


77
Sleep contributors


47
53


ŌURA
75
Feeling refreshed?
82

Withings ScanWatch hybrid smartwatch

https://www.withings.com/be/en/scanwatch

Apple Watch

https://www.apple.com/healthcare/apple-watch/

Video

https://www.youtube.com/watch?v=Kesk2rko-6I

Results: From 1 year of tracking, mean number of valid wear days were 292 (SD = 86), i.e. 80%. The Polar M430 provides acceptable measurements for total energy expenditure. Motivations for increased wear time were that participants were asked to wear it and the ability to track PA progress. Perceived usefulness included time keeping, heart rate- and sleep tracking, becoming more conscious about day-to-day activity, and improved understanding of which activity types were more effective for energy expenditure. Sources of AT annoyance were measurement inaccuracies and limited instruction for use. Suggestions for improvement were that the AT was big, unattractive, and complicated to use.

Henriksen, A., Sand, A-S., Deraas, T., Grimsgaard, S., Hartvigsen, G., Hopstock, L. Succeeding with prolonged usage of consumer-based activity trackers in clinical studies: A mixed methods approach. *BMC Public Health* 20, 1300 (2020). DOI: 10.1186/s12889-020-09406-w PMID: 32854671

BMC Public Health

RESEARCH ARTICLE Open Access

Succeeding with prolonged usage of consumer-based activity trackers in clinical studies: a mixed methods approach

André Henriksen, Anne-Sofie Sand, Trygve Deraas, Sameline Grimsgaard, Gunnar Hartvigsen and Laila Hopstock

Abstract

Background: Lack of physical activity (PA) is a risk factor for death and non-communicable disease. Despite this, more than one fourth of adults worldwide do not follow PA guidelines. As part of a feasibility study to test a complex intervention for increasing PA, we included a consumer-based activity tracker (AT) as a tool to measure PA outcomes and its task heart rate during exercise sessions. The aim of the present study was to identify factors that increase wear time when using a consumer-based AT for monitoring of participants in clinical research.

Methods: Sixteen participants aged 55–74 years, with obesity, sedentary lifestyle, and elevated cardiovascular risk were recruited to a 12-month feasibility study. Participants wore a Polar M430 AT to collect continuous PA data during a six-month intervention (followed by 6 months of follow-up). We performed quantitative wear time analysis, tested the validity of the AT, and completed two rounds of qualitative interviews to investigate how individual wear-time was linked to participant responses.

Results: From 1 year of tracking, mean number of valid wear days were 292 (SD = 86), i.e. 80%. The Polar M430 provides acceptable measurements for total energy expenditure. Motivations for increased wear time were that participants were asked to wear it and the ability to track PA progress. Perceived usefulness included time keeping, heart rate- and sleep tracking, becoming more conscious about day-to-day activity, and improved understanding of which activity types were more effective for energy expenditure. Sources of AT annoyance were measurement inaccuracies and limited instruction for use. Suggestions for improvement were that the AT was big, unattractive, and complicated to use.

Conclusions: Adherence to wearing a consumer-based AT was high. Results indicate that it is feasible to use a consumer-based AT to measure PA over a longer period. Potential success factors for increased wear time includes adequate instruction for AT use, allowing participants to choose different AT designs, and using trackers with accurate measurements. To identify accurate trackers, AT validation studies in the target cohort may be needed.

Trial registration: U.S. National Library of Medicine, Clinical Trial registry: NCT03807323. Registered 16 September 2019 – Retrospectively registered.

Keywords: Actigraphy, Human activity, Activity trackers, Motor activity, Intervention study, Clinical trial, Polar M430

Etiske utfordringer

- Registering av helserelaterte data

Methods

Sixteen participants aged 55–74 years, with obesity, sedentary lifestyle, and elevated cardiovascular risk were recruited to a 12-month feasibility study. Participants wore a Polar M430 AT to collect continuous PA data during a six-month intervention followed by 6 months of follow-up. We performed quantitative wear time analysis, tested the validity of the AT, and completed two rounds of qualitative interviews to investigate how individual wear-time was linked to participant responses.

Etiske utfordringer

- Del av klinisk studie

Trial registration

U.S. National Library of Medicine, Clinical Trial registry: NCT03807323; Registered 16 September 2019 – Retrospectively registered.

Availability of data and materials

The data/transcripts used during the current study are available from the corresponding author on reasonable request

Etisk problemstilling

- ER det dekning for dette i
  - REK godkjenningen?
  - Samtykket?
- Hvor lagres data?

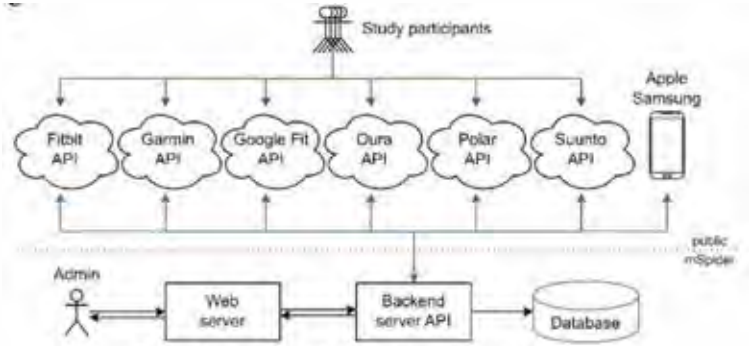


Figure 1. Original mSpider data collection architecture.

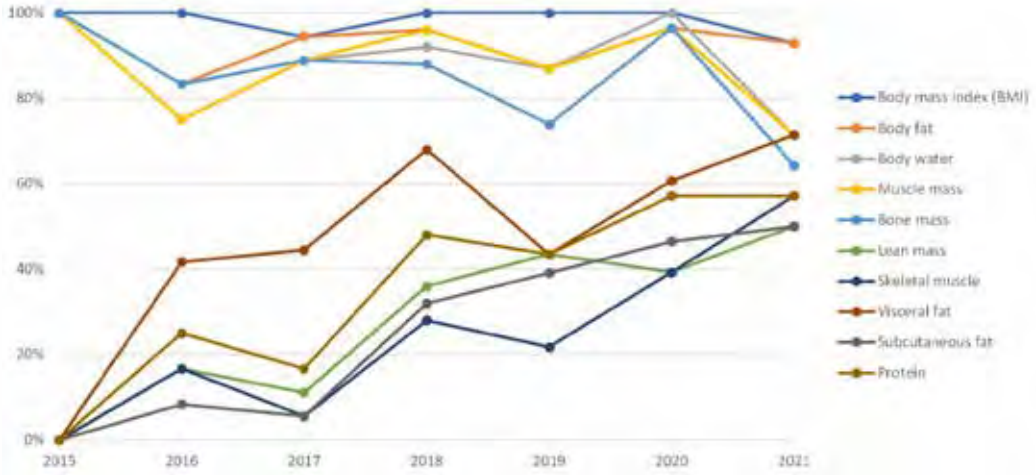


Fig. 4. Smart scale variable trends for the years 2015–2021.

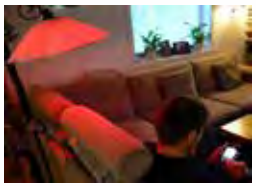
Johannessen, E., Johansson, J., Horsch, A., Årsand, E., Hartvigsen, G., Henriksen, A., Collecting Health-Related Research Data Using Consumer-Based Wireless Smart Scales. *International Journal of Medical Informatics,* May 2023, Vol 173, 105043. https://doi.org/10.1016/j.ijmedinf.2023.105043 PMID: 36934610

Health Research Requires Efficient Platforms for Data Collection from Personal Devices

Johannessen, E., Henriksen, A., Årsand, E., Horsch, A., Johansson, J., Hartvigsen, G., Health research requires efficient platforms for data collection from personal devices. *Studies in Health Technology and Informatics* 2023 May 18;302:841-845. doi: 10.3233/SHTI230286. PMID: 37203514


Ishavskatedralen
14. november
Case:
Diabetes
Pasienter med diabetes (type 1 og type 2)

20+ år med m-diabetes



Parents Comm.

Health care comm.

Electronic disease surveillance

Visual aids

Serious games

HUBRO server

Smart step counter

BG Bluetooth adapter

T2D app ver.1

T1D, Photo Diary, Children

T2D, RCT

T2D app ver.2

BG Bluetooth prototype

T1D, SMS Child → parents

Diabetes Diary Android versjon

Diabetes Diary iPhone versjon

Robots

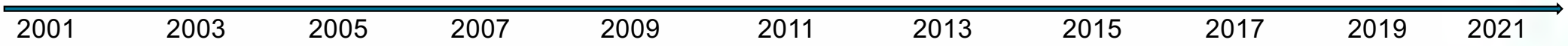
Juice machine

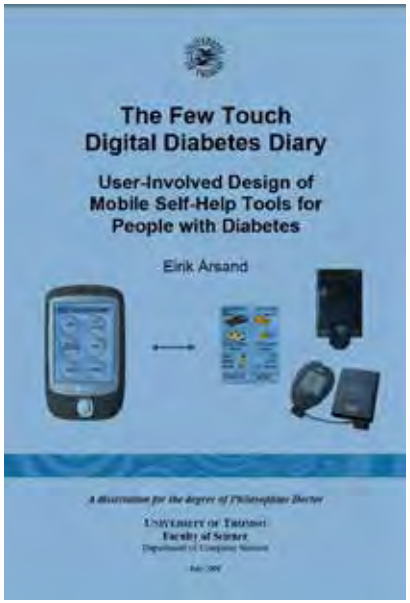
Risk factors (AI)

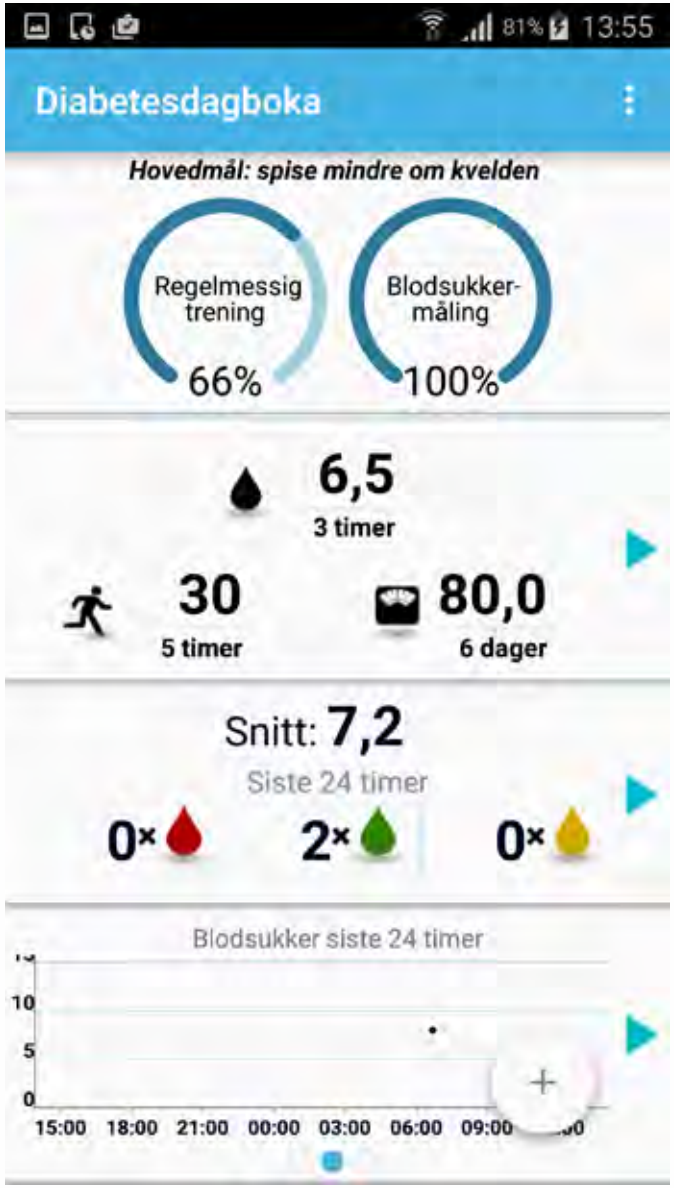
BG prediction

Motivation groups

Pebble app







Eksempel på vår forskning som brukes av tusenvis av pasienter ...

Utviklet i nært samarbeid med brukerne (personer med diabetes)

F.eks. 12 personer med diabetes type 2 engasjert over 3 år, ved hjelp av følgende metoder:

- Fokusgruppe (á 5-8 personer)
- Paper prototyping / skissering øvelse
- Tenker høyt
- Spørreskjema
- Intervju
- Automatisk logging
- «Lekser» mellom møtene
- Prototyping – (re)testing

Motivasjonsgrupper (T2D)

«Appen gjør hverdagen lettere»

3.1.1 Approval by Ethical Committees

- The World Medical Association Declaration of Helsinki [375] states among other things: “The health of my patient will be my first consideration”. This declaration is essential in clinical research (involving patients) and it is administered by local ethical committees. For all of the three studies that involved patients (the Type 2 cohort, the Type 1 cohort and the **US cohort**), an application describing the protocol and the risks of the project was written and sent to the local Regional Ethical Committee (REK).
- For the main cohort, (Type 2) this was done in February 2006 and approved later that year. After receiving a detailed explanation of the project as a whole, the right to withdraw at any time, and other practicalities, the study participants gave written informed consent to their participation. For the Type 1 cohort, the protocol was approved by REK in 2003, and for the US cohort, approval was received in 2007

Performance of the First Combined Smartwatch and Smartphone Diabetes Diary Application Study

Erik Årsand, PhD[1,2], Miroslav Muzny, M.Sc.[1,2], Meghan Bradway, MBA[1,2], Jan Muzik, PhD[3], and Gunnar Hartvigsen, PhD[1,2]

Årsand, E., Muzny, M., Bradway, M., Muzik, J., Hartvigsen, G. Performance of the first Combined Smartwatch to Smartphone Diabetes Diary Application Study. *Diabetes Science and Technology Journal 2015,* May;9(3):556–63. doi: 10.1177/1932296814567708. PMID: 25591859.

“Performance of the First Combined Smartwatch to Smartphone Diabetes Diary Application Study”

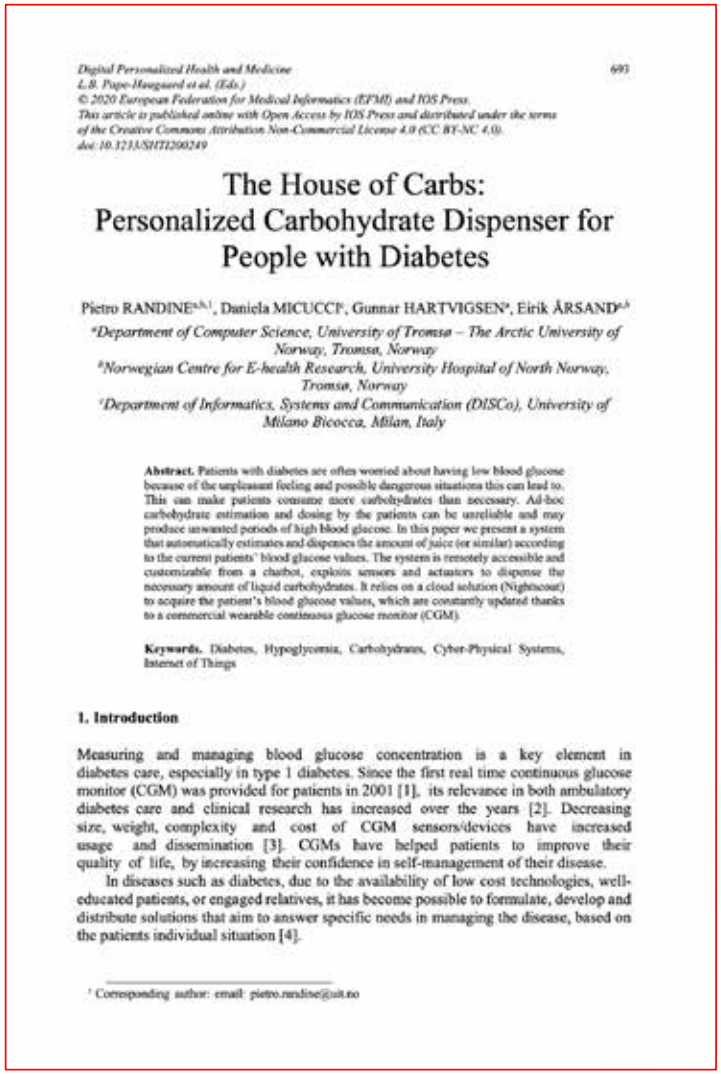
Figur 1. A-F: Innføring av karbohydratinntak, insulinenheter og blodsukkermålinger gjøres ved hjelp av den midterste knappen. Tidligere registreringer vises med nederste knapp til høyre. Spesifikke fysiske aktiviteter registreres ved hjelp av knappen øverst til høyre. Automatisk påminnelse om blodsukkermåling er satt til 90 minutter etter måltider som standard.

Test Phase

- The system's feasibility was tested by 6 people with type 1 diabetes over two weeks during summer 2014. Recruitment was completed through an earlier NST project and affiliates from Motol University Hospital, Prague. To assess users' perceptions and expectations of a smartwatch-based diabetes diary, without knowledge of the features being tested, we asked the 6 participants to fill in a pretest questionnaire. For quality assurance, we performed face-to-face meetings where the apps functionalities were demonstrated. We also distributed a User Guide, including a troubleshooting section for known issues identified through continuous development that were still being modified. We also offered support via e-mail and phone. To ensure timely, detailed and relevant feedback, a period of two weeks was chosen for the posttest survey. The users were given a Pebble smartwatch that they could keep and also use after the test, but were asked to use their own Android smartphone. The small number of participants was deliberately chosen to ensure an efficient use of resources on a novel system. The concept should be followed up in a larger study to reveal medical and long-term effects of usage. No personal data was stored or transferred, that is, no institutional review board acknowledgment was found to be necessary.

House of Carbs

Randine, P., Micucci, D., Hartvigsen, G., Årsand, E., The House of Carbs: Personalized Carbohydrate Dispenser for People with Diabetes. *Studies in Health Technology and Informatics,* 2020;270:693-697. DOI: 10.3233/SHTI200249. PMID: 32570472



Digital Personalized Health and Medicine 693
L.B. Pape-Haugaard et al. (Eds.)

doi: 10.3233/SHTI200249

The House of Carbs:
Personalized Carbohydrate Dispenser for People with Diabetes

Pietro RANDINE[a,b,1], Daniela MICUCCI[c], Gunnar HARTVIGSEN[a], Eirik ÅRSAND[a,b]
[a]*Department of Computer Science, University of Tromsø – The Arctic University of Norway, Tromsø, Norway*
[b]*Norwegian Centre for E-health Research, University Hospital of North Norway, Tromsø, Norway*
[c]*Department of Informatics, Systems and Communication (DISCo), University of Milano Bicocca, Milan, Italy*

Abstract. Patients with diabetes are often worried about having low blood glucose because of the unpleasant feeling and possible dangerous situations this can lead to. This can make patients consume more carbohydrates than necessary. Ad-hoc carbohydrate estimation and dosing by the patients can be unreliable and may produce unwanted periods of high blood glucose. In this paper we present a system that automatically estimates and dispenses the amount of juice (or similar) according to the current patients' blood glucose values. The system is remotely accessible and customizable from a chatbot, exploits sensors and actuators to dispense the necessary amount of liquid carbohydrates. It relies on a cloud solution (Nightscout) to acquire the patient's blood glucose values, which are constantly updated thanks to a commercial wearable continuous glucose monitor (CGM).

Keywords. Diabetes, Hypoglycemia, Carbohydrates, Cyber-Physical Systems, Internet of Things

1. Introduction

Measuring and managing blood glucose concentration is a key element in diabetes care, especially in type 1 diabetes. Since the first real time continuous glucose monitor (CGM) was provided for patients in 2001 [1], its relevance in both ambulatory diabetes care and clinical research has increased over the years [2]. Decreasing size, weight, complexity and cost of CGM sensors/devices have increased usage and dissemination [3]. CGMs have helped patients to improve their quality of life, by increasing their confidence in self-management of their disease.

In diseases such as diabetes, due to the availability of low cost technologies, well-educated patients, or engaged relatives, it has become possible to formulate, develop and distribute solutions that aim to answer specific needs in managing the disease, based on the patients individual situation [4].

[1] Corresponding author: email: pietro.randine@uit.no

Video

https://www.youtube.com/watch?v=-f2rK3T6SvE


En av våre
brukere ...

Video

https://www.youtube.com/watch?v=skkF_Njzsjo&t=4s


Hva sier
spesialisten?

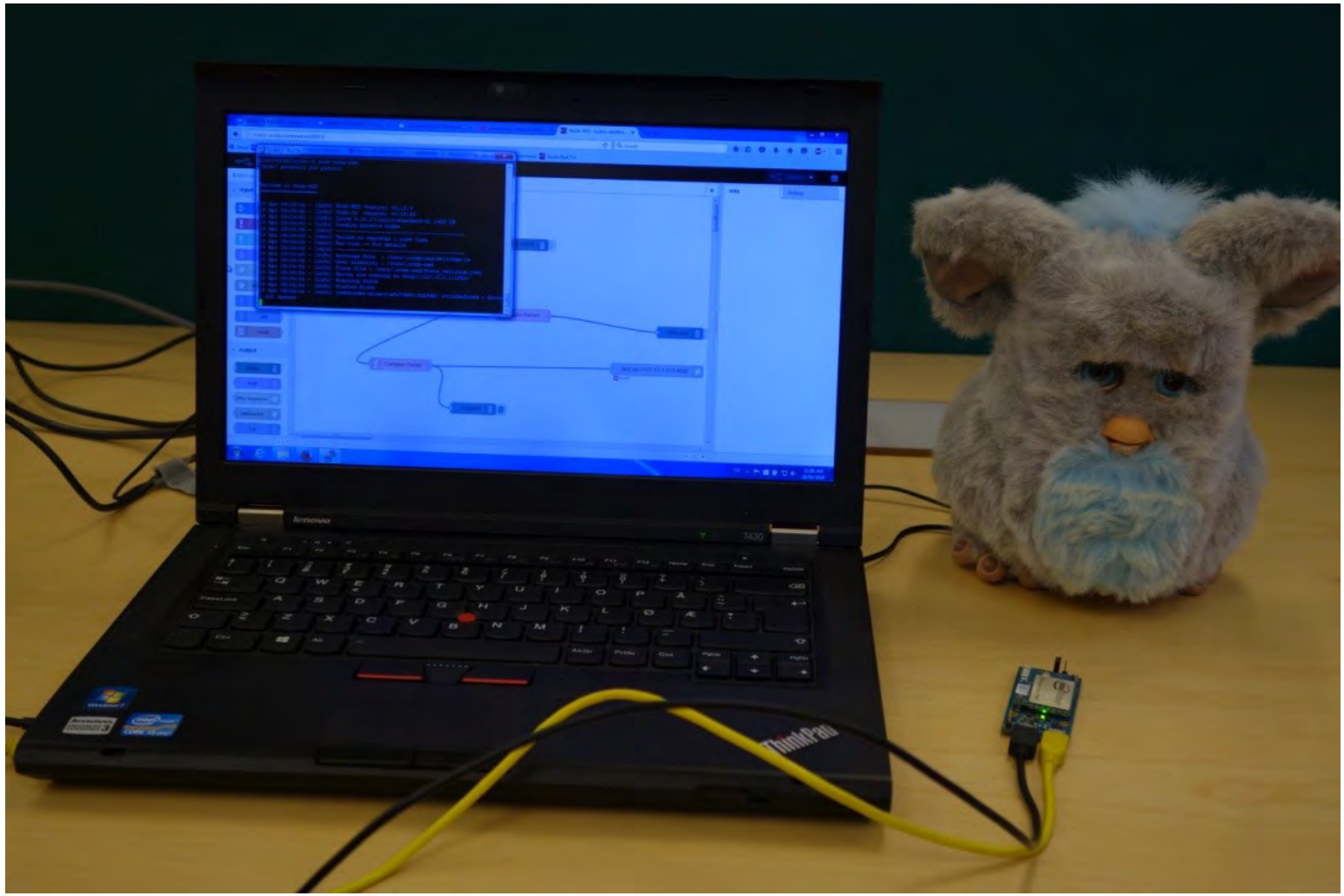
Video

https://www.youtube.com/watch?v=skkF_Njzsjo&t=4s

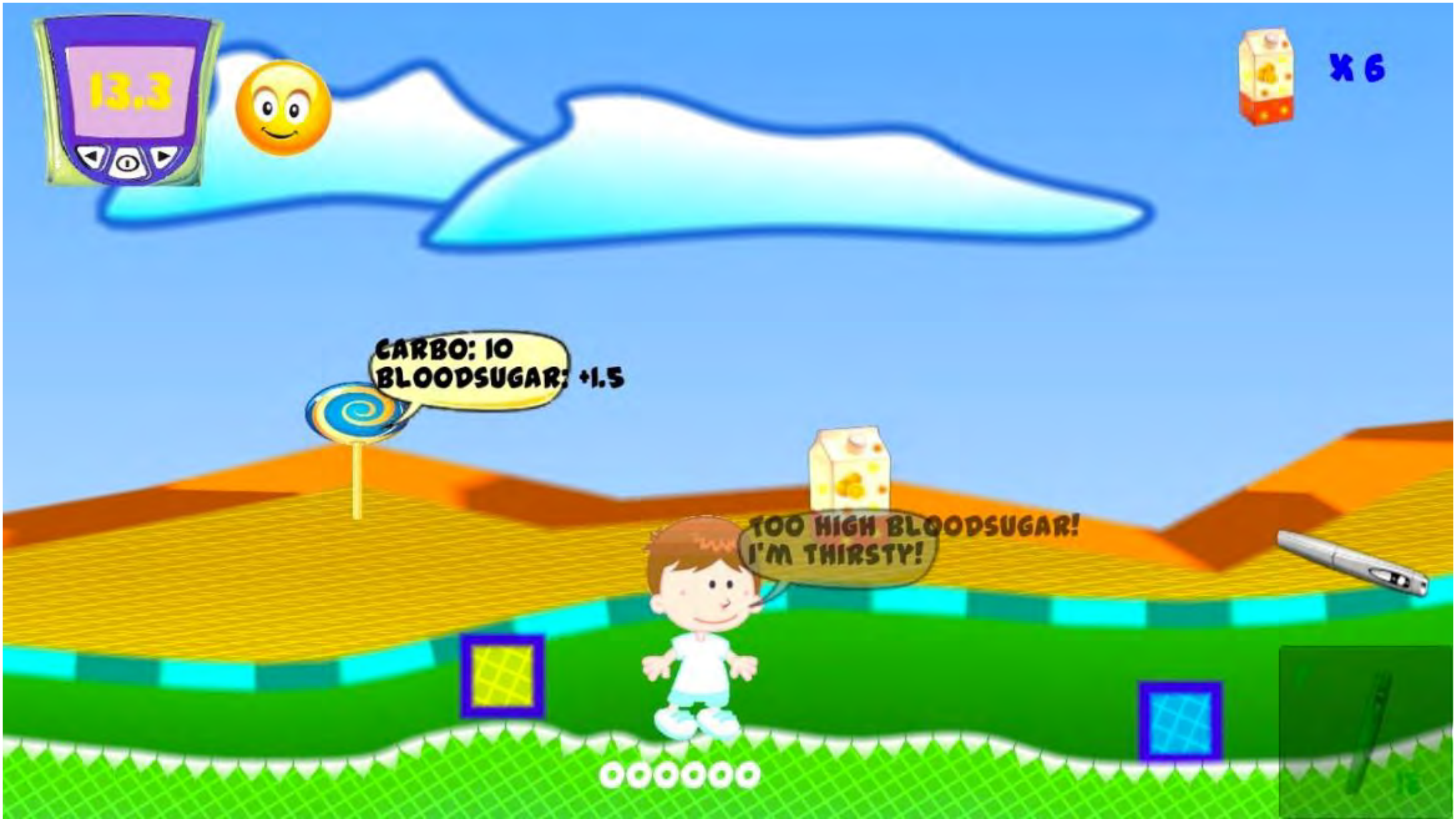
Eksempel:
Kommunikasjon barn – forelder

Tradisjonell blodsukkermåling

Fungerer også med CGM



Randine, P., Muzny, M., Micucci, D., Hartvigsen, G., Årsand, E., Transforming a Furby toy to a multi-modal companion for children with Type 1 diabetes. *Diabetes Technology & Therapeutics*. February 2020, 22(S1): A-161-162


13.3
x 6
CARBO: 10
BLOODSUGAR: +1.5
TOO HIGH BLOODSUGAR!
I'M THIRSTY!


4.9
x 7
KARBO: 25
BLODSUKKER: +0
KARBO: 25
BLODSUKKER: +0
KARBO: 40
BLODSUKKER: +0
KARBO: 40
BLODSUKKER: +0
Developer: Alexandra Makhlysheva

3.6 Summary

The following methods were used for this project:

- System design (engineering approach)
- Data collection
  - Literature review
  - Meeting with children
  - Discussions with experts and colleagues
  - Meeting with doctors
- Experimentation
  - Questionnaires for parents and children
  - Game testing
  - Questionnaire and verbal questions for barn after testing
- Evaluation (qualitative method)

DIAQUARIUM

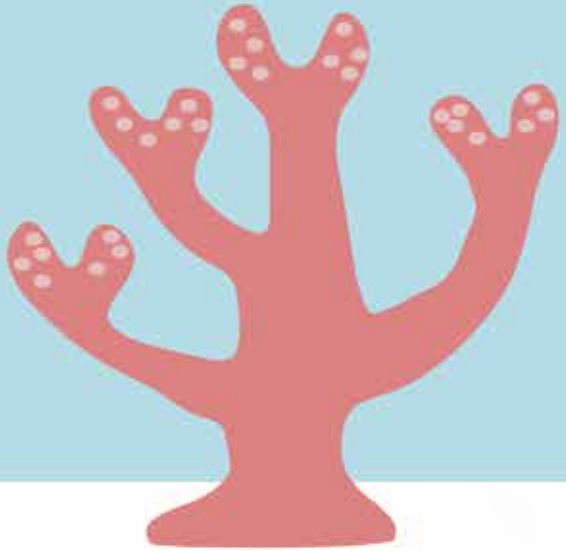
0 x

1/5

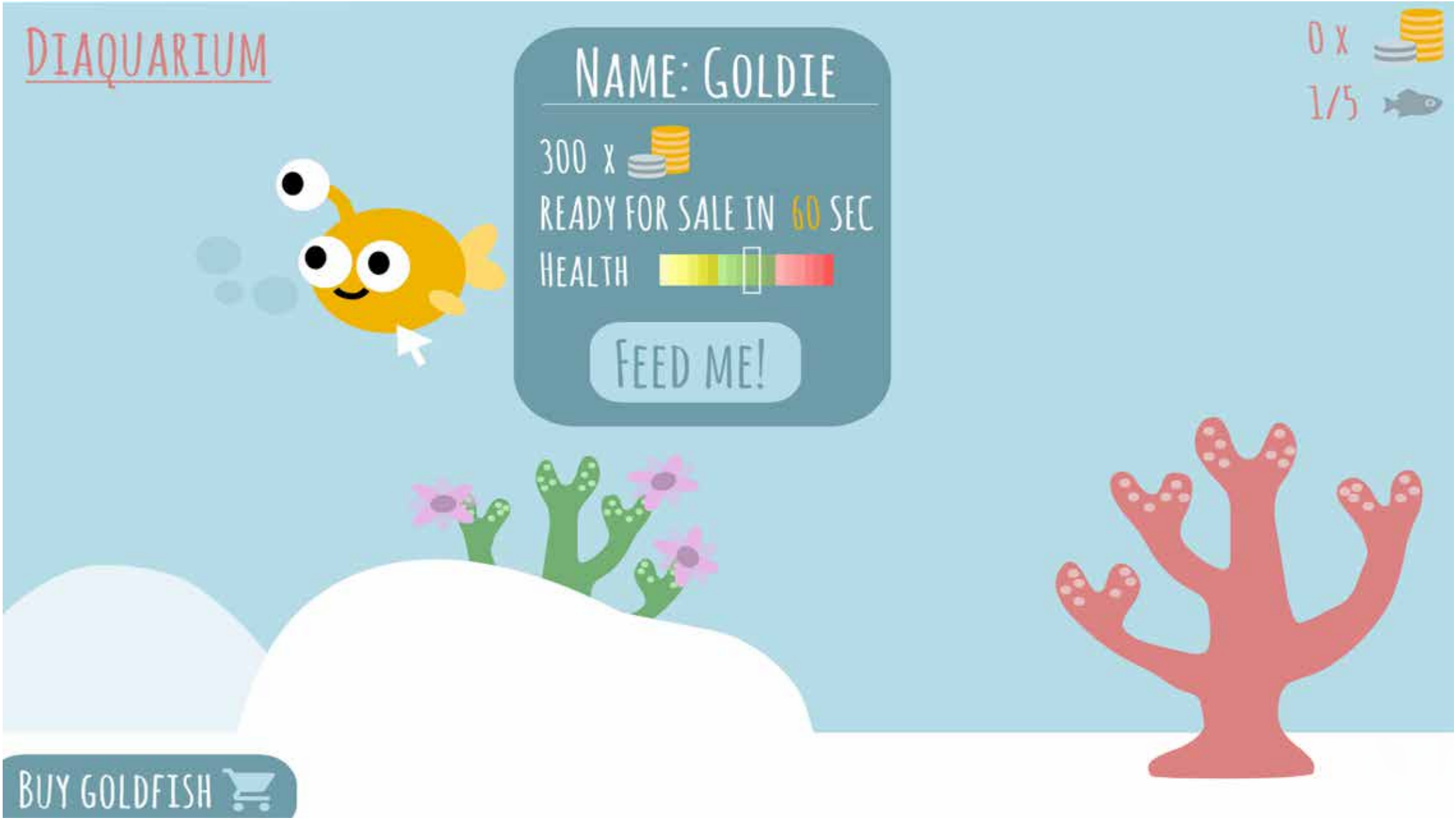
WELCOME TO DIAQUARIUM!

AN ACUARIUM WHERE ALL GOLDFISH HAVE DIABETES. YOU MUST TAKE GOOD CARE OF THEM UNTIL THEY ARE READY TO BE SOLD. YOU CAN BUY NEW GOLDFISH FOR THE GOLD YOU EARN.

LET'S PLAY!



BUY GOLDFISH


DIAQUARIUM
0 x
1/5
NAME: GOLDIE
300 x
READY FOR SALE IN 60 SEC
HEALTH
FEED ME!
BUY GOLDFISH


DIAQUARIUM
PREPARE A MEAL
0 x
1/5
INSULIN
1
2
3
4
5
6
7
LET'S EAT!
BUY GOLDFISH

← BACK

GOLDFISH BOUTIQUE

0 x

3/5

NAME: GILL

1000 x

READY FOR SALE IN 300 SEC

$500

NAME: CLEO

50 x

READY FOR SALE IN 100 SEC

$20

NAME: GOLDIE

300 x

READY FOR SALE IN 200 SEC

$150

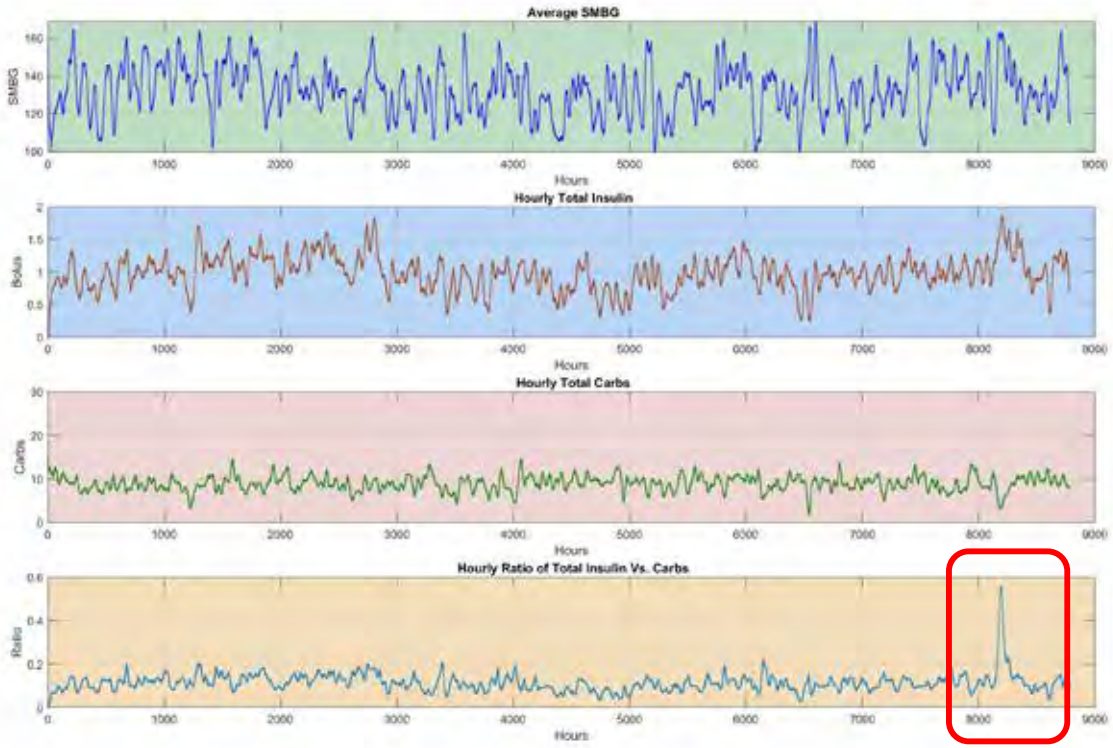
Etiske problemstillinger

- Forskning som involverer barn
- Helsedata fra barn
- Samtykke

Disease surveillance

Å oppdage spredning av smittsomme sykdommer før de som er smittet vet at de er smittet.

Disease surveillance



Etiske problemstillinger

- Benyttet anonymiserte data fra 4 personer med diabetes type 1
  - Glukosemålinger
  - Insulin
  - Karbohydrater
  - Fysisk aktivitet
- Personene var kjent for forskerteamet
- Forskere fra USA og Tsjekkia


Case:
Intellektuell
funksjonsnedsettelse

PA-ID

(HELSE NORD)

Økt fysisk aktivitet for personer med psykisk utviklingshemming

Background

- **Effects of Physical Activity with e-health support in Individuals with Intellectual Disabilities. A randomised controlled study**
- 2017-2023 (extended to 2025)
- Euro 0,36 mill. (1 research scholar)
- *Project manager, professor and senior doctor Audny Anke, Department of Rehabilitation, UNN & Univ. of Tromsø – The Arctic Univ. of Norway*
- *Technical manager, professor Gunnar Hartvigsen, Univ. of Tromsø – The Arctic Univ. of Norway*
- *PhD candidate: Henriette Michalsen, psychologist, UNN*

Effects of Physical Activity with e-health support in Individuals with Intellectual Disabilities. A randomised controlled study

1.1 Relevance relative to the call for proposals

The main objective of this project is to enhance physical activity in youths and adults with intellectual disabilities (IDs). Compared with the general population individuals with IDs have worse health, lower levels of activity, and greater barriers to participating in fitness activities and accessing established health care systems. In a recent review, only 9% of individuals with IDs achieved the minimum physical activity guidelines. As low physical activity is a determinant of health, and as increasing activity has positive effects on cardiovascular and psychosocial health, identifying effective interventions for use in everyday settings is exceedingly important. Studies conducted to increase physical activity in people with ID are often non-randomised, in non-natural settings, and not theory-based and often exclude people with more severe ID. Recent well-designed studies in this field have failed to demonstrate improved levels of physical activity in intervention groups. Accordingly, the aims of this project are three-fold: 1) to integrate theory with users' needs to design a flexible person-centred physical activity programme using motivational e-health support in natural settings; 2) to investigate the effects of this physical activity programme in youth and adults with ID in a randomised controlled trial; and 3) to increase research activity and national and international cooperation in this in Norway low-research field. Users and user-organisations are involved in all stages and in study management.

1.2 Aspects of the research project

Background and status of knowledge

In Norway, approximately 18.000 adults with IDs require health and social services from the municipalities (www.regjeringen.no). Individuals with intellectual disabilities (IDs) have worse health than the general population,[1-4] more unmet health care needs and more difficulty accessing healthcare.[5-7] Low physical activity and weight disturbances are health determinants that more prevalent in people with ID than in the general adult population.[8-12] A sedentary life style has been found in approximately 50% and low physical activity in 40% of this population.[13] In a Norwegian study, 7% of men and 8% of women with Down syndrome met the current Nordic physical activity recommendation of 30 minutes or more of moderate physical activity each day (Nordic Council, 2005). A recent review found that 9% of people with ID worldwide achieved the WHO's minimum physical activity guidelines.[14] Meeting the physical activity guidelines was positively correlated with male gender, younger age, milder ID, and living without supervised care.[14] In the general population, a more sedentary lifestyle has become a pronounced problem in younger people,[15] and is assumed to be a greater problem in youth with ID.[16] Low levels of physical activity could be due to barriers, such as scarcity of available resources and opportunities or a lack of motivation.[17-19]

Previous physical activity intervention programmes

Physical activity is a modifiable risk factor for chronic diseases and a potentially important way to improve health.[20] Several studies have reported on the effects of physical activity interventions for individuals with ID on physical fitness indicators, such as balance, muscle strength, and quality of life.[21-23] Furthermore, a review found a moderate level of evidence that sport-related activities seem to contribute to well-being and perception of social competence.[24] A multi-component intervention in Sweden to improve diet and physical activity in individuals with ID in community residences showed positive effects on levels of physical activity and work routines.[19] However, only adults with mild to moderate IDs were included, and effect sizes were small. A recent theory-based randomised controlled study of adults with all types of ID did not find any significant increases in levels of physical activity (steps per day).[25] Furthermore, the results of a recent cluster-randomised

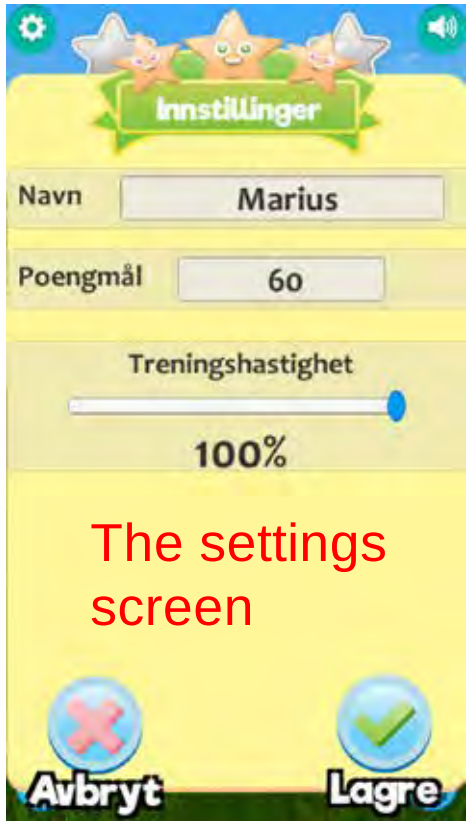
1

Multidisciplinary team

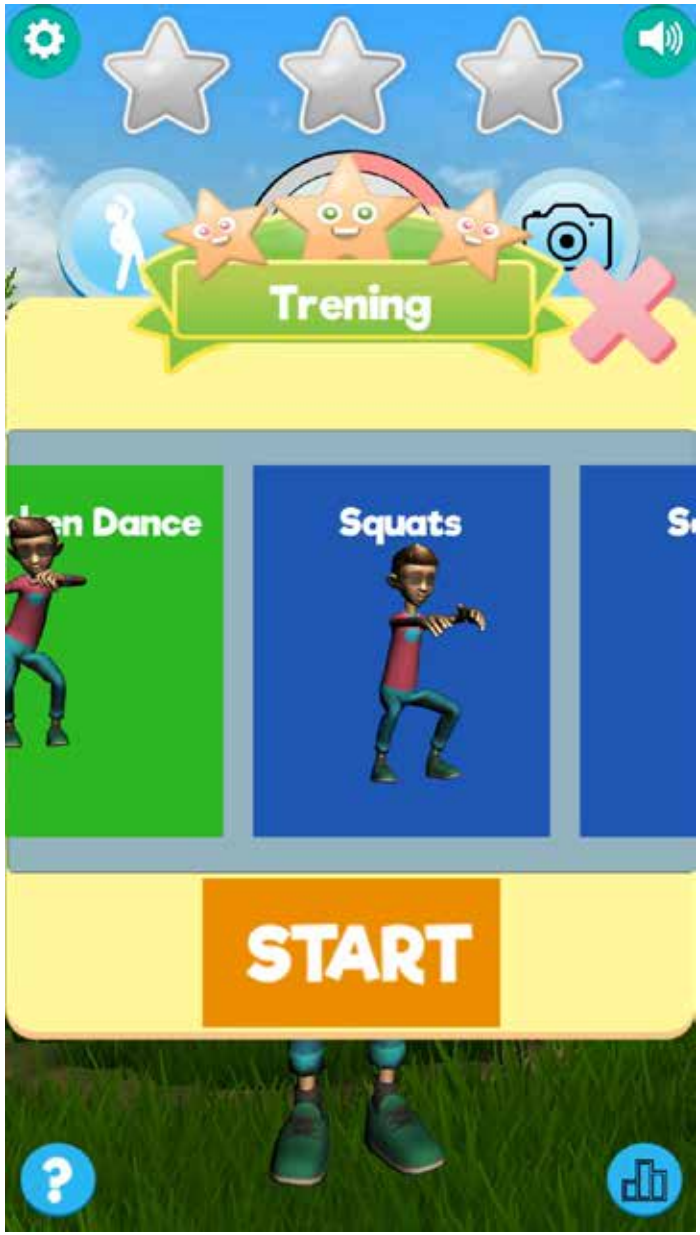
The research team has the qualifications and resources needed to complete the study, including competence in specialised and municipality-based habilitation, rehabilitation, physical activity in persons with disabilities, scientific competence of e-health and broad user experience.

- Professor Audny Anke, Dept. of Rehabilitation, UNN and Univ. of Tromsø – The Arctic Univ. of Norway (UiT)
- PhD-student Henriette Michalsen, psychologist, UNN
- Professor Gunnar Hartvigsen, health informatics, UiT
- Professor Silje Wangberg, physologist, UiT
- Professor Gunn Pettersen, sociologist, UiT
- Professor Cathrine Arntzen, health science, UiT
- Assoc. prof. Gyrd Thrane, physiotherapist, UiT
- Ass. prof. André Henriksen, health informatics, UiT
- Ass. prof. Anita Tymi, The Norwegian Association for Persons with Developmental Disabilities (NFU)
- senior adviser Edel Pedersen, The municipality of Tromsø
- Executive Chair Professor Cecilie Røe, Research Centre for Habilitation and Rehabilitation Models and Services (CHARM), University of Oslo (UiO)


Treningsrom Tindfoten dagsenter



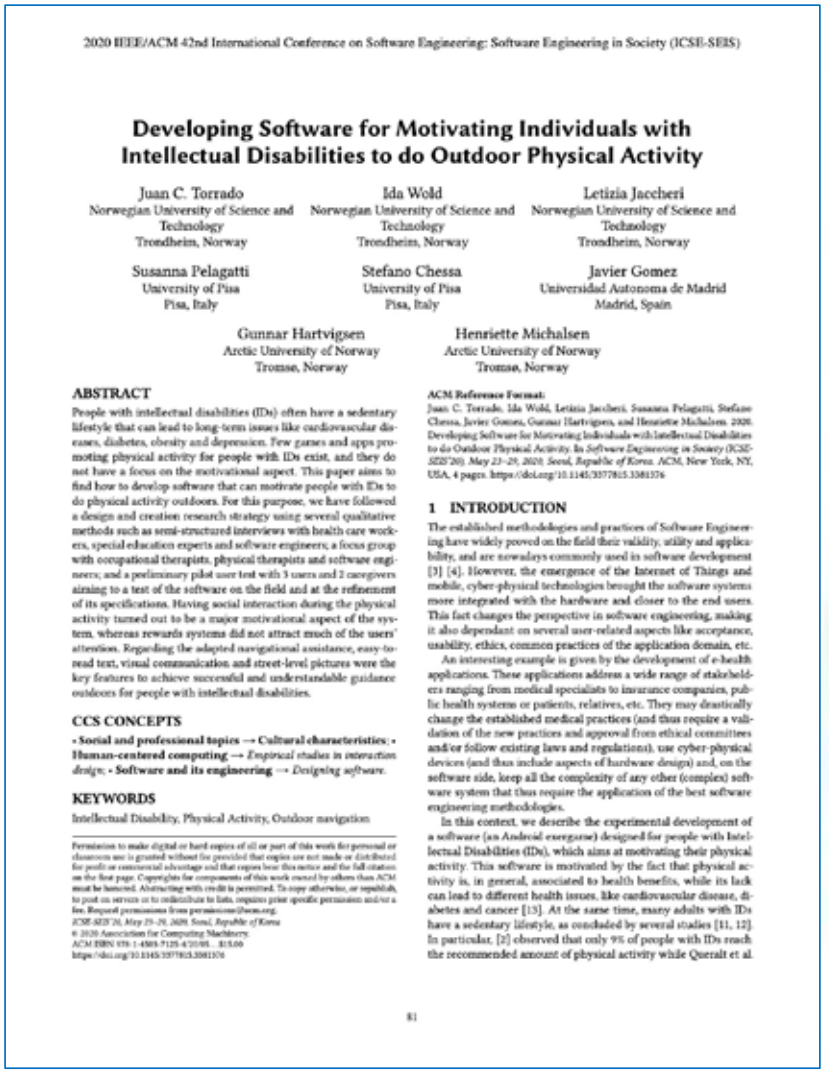
Exercise selection screen



Sorterius – Demo

Abstract: People with intellectual disabilities (IDs) often have a sedentary lifestyle that can lead to long-term issues like cardiovascular diseases, diabetes, obesity and depression. Few games and apps promoting physical activity for people with IDs exist, and they do not have a focus on the motivational aspect. This paper aims to find how to develop software that can motivate people with IDs to do physical activity outdoors. For this purpose, we have followed a design and creation research strategy using several qualitative methods such as semi-structured interviews with health care workers, special education experts and software engineers; a focus group with occupational therapists, physical therapists and software engineers; and a preliminary pilot user test with 3 users and 2 caregivers aiming to a test of the software on the field and at the refinement of its specifications. Having social interaction during the physical activity turned out to be a major motivational aspect of the system, whereas rewards systems did not attract much of the users' attention. Regarding the adapted navigational assistance, easy-to-read text, visual communication and street-level pictures were the key features to achieve successful and understandable guidance outdoors for people with intellectual disabilities

Torrado, J.C., Wold, I., Jaccheri, L., Pelagatti, S., Chessa, S., Gomez, J., Hartvigsen, G., Michalsen, H. Developing Software for Motivating Individuals with Intellectual Disabilities to do Outdoor Physical Activity. 2020 IEEE/ACM 42nd International Conference on Software Engineering in Society (ICSE-SEIS 2020), (Virtual conference due to the pandemic, June 27 – July 19, 2020). pp. 81-84. Publisher: ACM (ISBN 978-1-4503-7125-4/20/05) (https://doi.org/10.1145/3377815.3381376)



2020 IEEE/ACM 42nd International Conference on Software Engineering: Software Engineering in Society (ICSE-SEIS)

Developing Software for Motivating Individuals with Intellectual Disabilities to do Outdoor Physical Activity

Juan C. Torrado
Norwegian University of Science and Technology
Trondheim, Norway

Ida Wold
Norwegian University of Science and Technology
Trondheim, Norway

Letizia Jaccheri
Norwegian University of Science and Technology
Trondheim, Norway

Susanna Pelagatti
University of Pisa
Pisa, Italy

Stefano Chessa
University of Pisa
Pisa, Italy

Javier Gomez
Universidad Autonoma de Madrid
Madrid, Spain

Gunnar Hartvigsen
Arctic University of Norway
Tromso, Norway

Henriette Michalsen
Arctic University of Norway
Tromso, Norway

ABSTRACT

People with intellectual disabilities (IDs) often have a sedentary lifestyle that can lead to long-term issues like cardiovascular diseases, diabetes, obesity and depression. Few games and apps promoting physical activity for people with IDs exist, and they do not have a focus on the motivational aspect. This paper aims to find how to develop software that can motivate people with IDs to do physical activity outdoors. For this purpose, we have followed a design and creation research strategy using several qualitative methods such as semi-structured interviews with health care workers, special education experts and software engineers; a focus group with occupational therapists, physical therapists and software engineers; and a preliminary pilot user test with 3 users and 2 caregivers aiming to a test of the software on the field and at the refinement of its specifications. Having social interaction during the physical activity turned out to be a major motivational aspect of the system, whereas rewards systems did not attract much of the users' attention. Regarding the adapted navigational assistance, easy-to-read text, visual communication and street-level pictures were the key features to achieve successful and understandable guidance outdoors for people with intellectual disabilities.

CCS CONCEPTS

• **Social and professional topics** → **Cultural characteristics**; • **Human-centered computing** → *Empirical studies in interaction design*; • **Software and its engineering** → *Designing software*.

KEYWORDS

Intellectual Disability, Physical Activity, Outdoor navigation

ICSE-SEIS'20, May 23–29, 2020, Seoul, Republic of Korea

ACM ISBN 978-1-4503-7125-4/20/05…$15.00
https://doi.org/10.1145/3377815.3381376

ACM Reference Format:
Juan C. Torrado, Ida Wold, Letizia Jaccheri, Susanna Pelagatti, Stefano Chessa, Javier Gomez, Gunnar Hartvigsen, and Henriette Michalsen. 2020. Developing Software for Motivating Individuals with Intellectual Disabilities to do Outdoor Physical Activity. In *Software Engineering in Society (ICSE-SEIS'20), May 23–29, 2020, Seoul, Republic of Korea.* ACM, New York, NY, USA, 4 pages. https://doi.org/10.1145/3377815.3381376

1 INTRODUCTION

The established methodologies and practices of Software Engineering have widely proved on the field their validity, utility and applicability, and are nowadays commonly used in software development [3] [4]. However, the emergence of the Internet of Things and mobile, cyber-physical technologies brought the software systems more integrated with the hardware and closer to the end users. This fact changes the perspective in software engineering, making it also dependant on several user-related aspects like acceptance, usability, ethics, common practices of the application domain, etc.

An interesting example is given by the development of e-health applications. These applications address a wide range of stakeholders ranging from medical specialists to insurance companies, public health systems or patients, relatives, etc. They may drastically change the established medical practices (and thus require a validation of the new practices and approval from ethical committees and/or follow existing laws and regulations), use cyber-physical devices (and thus include aspects of hardware design) and, on the software side, keep all the complexity of any other (complex) software system that thus require the application of the best software engineering methodologies.

In this context, we describe the experimental development of a software (an Android exergame) designed for people with Intellectual Disabilities (IDs), which aims at motivating their physical activity. This software is motivated by the fact that physical activity is, in general, associated to health benefits, while its lack can lead to different health issues, like cardiovascular disease, diabetes and cancer [13]. At the same time, many adults with IDs have a sedentary lifestyle, as concluded by several studies [11, 12]. In particular, [2] observed that only 9% of people with IDs reach the recommended amount of physical activity while Queralt et al.

Sykling

(innendørs, utendørs)


tacx

Video

https://vimeo.com/296196563

Results Three main themes were identified. According to support persons, motivation could be promoted at the individual level by fun, mastery, social setting, technology and knowledge about health behaviours. At a contextual level, physical activity was mediated by engagement with support individuals and available resources. At an interactional level, individuals were more motivated if the interaction was featured by joint activities, predictability and the use of rewards.

Family members and health care workers' perspectives on motivational factors of participation in physical activity for people with intellectual disability: A qualitative study

H. Michalsen, S. C. Wangberg, A. Anke, G. Hartvigsen, L. Jaccheri & C. Arntzen

Abstract

Michalsen, H., Wangberg, S.C., Anke, A., Hartvigsen, G., Jaccheri, L., Arntzen, C. Family members and health care workers' perspectives on motivational factors of participation in physical activity for people with intellectual disability: A qualitative study. *Journal of Intellectual Disability Research*, 64(4), 259-270 (Apr 2020) https://doi.org/10.1111/jir.12716. PMID: 31981261

Video

https://vimeo.com/334205361

Objective: We aim to assess the feasibility and acceptability of procedures for an intervention arm in a future trial on mobile health (mHealth) to support PA for individuals with IDs. In addition, we aim to examine how the use of technology can influence motivation for PA among participants, their caregivers, and staff members.

Conclusions: This pilot study will evaluate the feasibility and acceptability of study procedures of the intervention arm of a planned RCT to address feasibility issues, improve study procedures, and estimate effectiveness of the study measures. How the use of technology can influence motivation for PA will also be examined, which can help guide and improve future PA interventions involving the use of technology.

Michalsen, H., Wangberg, S.C., Hartvigsen, G., Henriksen, A., Pettersen, G., Jaccheri, L., Jahnsen, R., Thrane, G., Arntzen, C., Anke, A. mHealth Support to Stimulate Physical Activity in Individuals With Intellectual Disability: Protocol for a Mixed Methods Pilot Study. *JMIR Research Protocols*. 2022; 11(9):e37849. 27/06/2022:37849 PMID: 36107473

JMIR RESEARCH PROTOCOLS

Protocol

mHealth Support to Stimulate Physical Activity in Individuals With Intellectual Disability: Protocol for a Mixed Methods Pilot Study

Henriette Michalsen[1], Carol Psychol, Silje C Wangberg[2], Prof Dr, Gunnar Hartvigsen[3], Prof Dr, Anne Henriksen[4], PhD, Guro Pettersen[5], Prof Dr, Letizia Jaccheri[6], Prof Dr, Reidun Birgitta Jahnsen[7], Prof Dr, Gyrd Thrane[8], PhD, Catherine Arntzen[9], PhD, Audny Anke[1,7], MD, Prof Dr

[1]Department of Rehabilitation, University Hospital of North Norway, Tromsø, Norway
[2]Department of Health and Care Sciences, Faculty of Health Sciences, UiT – The Arctic University of Norway, Narvik, Norway
[3]Department of Computer Science, Faculty of Science and Technology, UiT – The Arctic University of Norway, Tromsø, Norway
[4]Department of Health and Care Sciences, Faculty of Health Sciences, UiT – The Arctic University of Norway, Tromsø, Norway
[5]Department of Computer Science, Faculty of Information Technology and Electrical Engineering, NTNU, Trondheim, Norway
[6]Institute of Health and Society, Research Centre for Habilitation and Rehabilitation Models and Services (CHARM), Faculty of Medicine, University of Oslo, Oslo, Norway
[7]Department of Clinical Medicine, Faculty of Health Sciences, UiT – The Arctic University of Norway, Tromsø, Norway

Corresponding Author:
Henriette Michalsen, Carol Psychol
Department of Rehabilitation
University Hospital of North Norway
Hansine Hansens vei 67
Tromsø, 9038
Norway
Phone: 47 41500304
Email: [redacted]

Abstract

Background: Several studies have shown that individuals with intellectual disabilities (IDs) have low levels of physical activity (PA), and intervention studies on PA suggest inconsistent evidence. The use of technology as a means of motivation for PA has yet to be extensively explored and needs to be further investigated.

Objective: We aim to assess the feasibility and acceptability of procedures for an intervention arm in a future trial on mobile health (mHealth) to support PA for individuals with IDs. In addition, we aim to examine how the use of technology can influence motivation for PA among participants, their caregivers, and staff members.

Methods: A mixed methods pilot study of an intervention arm will be carried out in a planned randomized controlled trial (RCT). Ten participants with ID and three caregivers or a staff member will be included. Information will always be provided by a caregiver or a staff member, or participants with ID if possible. Assessments will be carried out at baseline, follow-up after 4 weeks, and 12 weeks, and include questionnaires on PA, social support, self-efficacy, and challenging behavior. PA will be measured with 2 different activity trackers (Fitbit and Axivity) for 1 week at all assessments. Feasibility will be assessed as recruitment and adherence rate, missing data, usability of the motivational mHealth tool, and estimates of effectiveness. Acceptability of study procedures, activity measures, and motivation for participation in PA will be additionally assessed with qualitative methods at the end of the intervention.

Results: Enrollment commenced in May 2021. Data collection was completed in March 2022.

Conclusions: This pilot study will evaluate the feasibility and acceptability of study procedures of the intervention arm of a planned RCT to address feasibility issues, improve study procedures, and estimate effectiveness of the study measures. How the use of technology can influence motivation for PA will also be examined, which can help guide and improve future PA interventions involving the use of technology.

Trial Registration: ClinicalTrials.gov NCT04929106; https://clinicaltrials.gov/ct2/show/NCT04929106

International Registered Report Identifier (IRRID): DERR1-10.2196/37849

Treningsapp (innendørs)

Design din egen avatar


Navn:
Trykk her...
Gutt
Karakter
Hår
Skjorte
Bukse
Sko
START


Ny
Stjerne
0%
Trening
Hei Marius. Velkommen tilbake. Ta en treningsøkt med meg

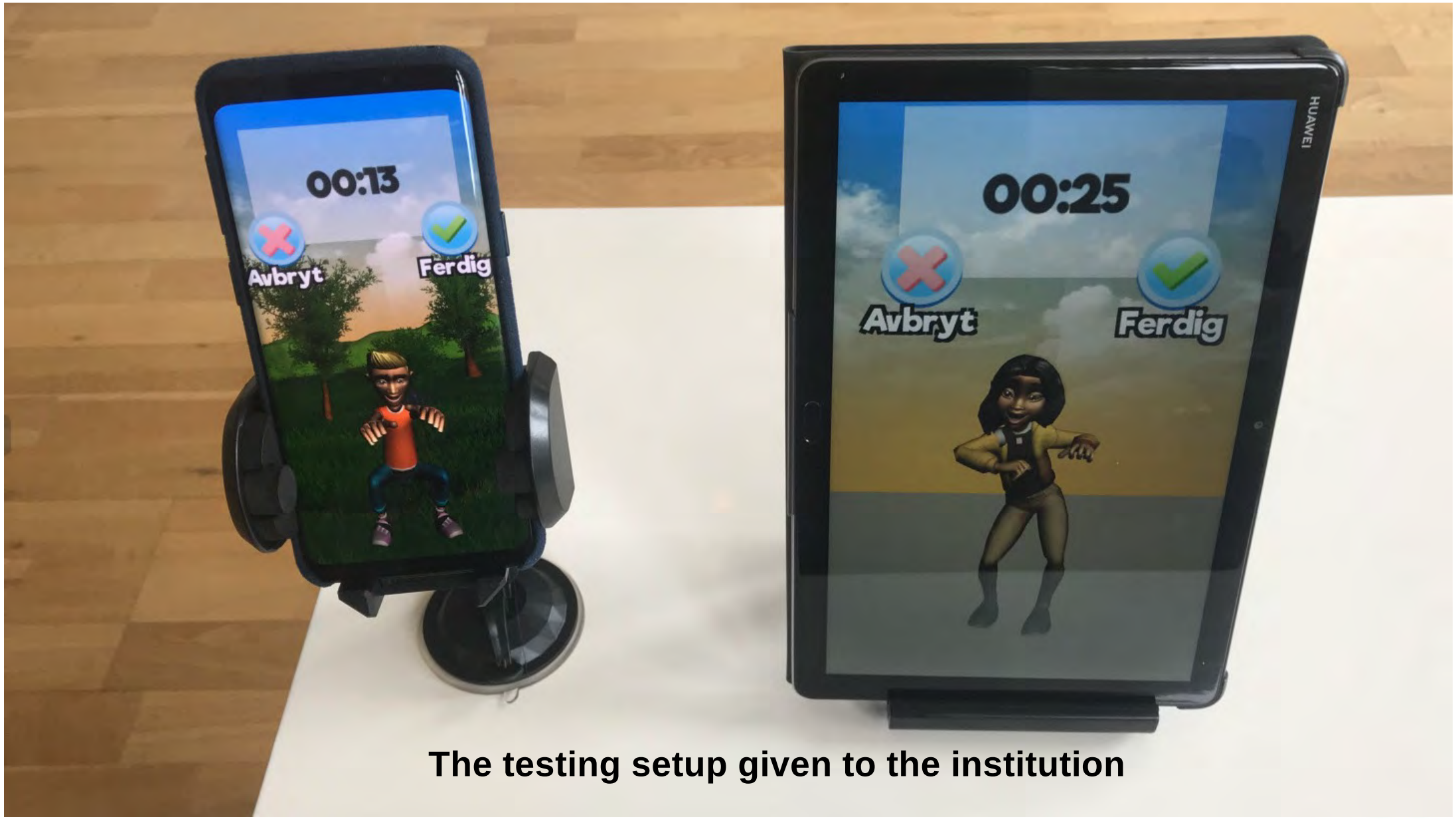

Ny
Stjerne
0%
Trening
Ta bilde


Ny
Stjerne
0%
Trening
Ta bilde


Ny
Stjerne
10%
Trening
Ta bilde


Ny
Stjerne
16%
Trening
Bra innsats
Marius! Du fikk 10
poeng. Stå på!


Bra jobbet!
Du tjente 22 poeng
og fikk en stjerne!
Kjempebra Marius!
LUKK



The testing setup given to the institution

The tablet set up in the training area

Abstract. Compared with the general population, people with intellectual disabilities have worse health, lower levels of activity, and greater barriers to participating in *fi*tness activities. Regular physical activity has positive effects on cardiovascular and psychosocial health and thus it is important to identify effective interventions for people with intellectual disabilities in everyday settings. In this position paper we present the design and development of proto- types of game-based eHealth solutions for behaviour change and health promotion by influencing physical activity. Participatory design and agile development have been applied in this project to deliver a system based on three solutions to promote, motivate and maintain physical activity in people with intellectual disabilities: Guided in-door bicycle exercise, guided out-door exer- cise and guided mild workouts. All the solutions provide virtual environments and motivation features adapted to people with intellectual disabilities for better engagement.

Berg, V., Haugland, V., Wiik, M.F., Michalsen, H., Anke, A., Muzny, M., Gomez, J., Martinez, S.G., Martinez-Millana, A., Henriksen, A., Sato, K., Hartvigsen, G. eHealth Approach for Motivating Physical Activities of People with Intellectual Disabilities. *IFIP Advances in Information and Communication Technology,* Vol 573 (2020), pp. 31-41.

eHealth Approach for Motivating Physical Activities of People with Intellectual Disabilities

Valter Berg[1], Vebjørn Haugland[1], Marius Fosbæg Wiik[1], Henriette Michalsen[1,2], Audrey Anke[1,2], Miroslav Muzny[2], Javier Gomez[3,4], Santiago Gil Martinez[5], Antonio Martinez-Millana[6], Andre Henriksen[1], Keiichi Sato[7], and Gunnar Hartvigsen[1(✉)]

[1] University of Tromsø – The Arctic University of Norway, 9037 Tromsø, Norway
gunnar.hartvigsen@uit.no
[2] University Hospital of North Norway, 9038 Tromsø, Norway
[3] Universidad Autónoma de Madrid, 28049 Madrid, Spain
[4] NTNU, 7491 Trondheim, Norway
[5] University of Agder, 4879 Grimstad, Norway
[6] ITACA, Universitat Politècnica de València, 46022 Valencia, Spain
[7] Illinois Institute of Technology, Chicago, IL 60616, USA

Abstract. Compared with the general population, people with intellectual disabilities have worse health, lower levels of activity, and greater barriers to participating in fitness activities. Regular physical activity has positive effects on cardiovascular and psychosocial health and thus it is important to identify effective interventions for people with intellectual disabilities in everyday settings. In this position paper we present the design and development of proto types of game-based eHealth solutions for behaviour change and health promotion by influencing physical activity. Participatory design and agile development have been applied in this project to deliver a system based on three solutions to promote, motivate and maintain physical activity in people with intellectual disabilities: Guided in-door bicycle exercise, guided out-door exercise and guided mild workouts. All the solutions provide virtual environments and motivation features adapted to people with intellectual disabilities for better engagement.

Keywords: Intellectual disability · eHealth · mHealth · Physical activity · Gamification

1 Introduction

Intellectual disabilities (IDs) are intellectual and functional impairments caused by a neurodevelopment disorder [1]. The prevalence of IDs ranges from 2 to more than 30 per 1,000 children [2], and the classification of IDs depends on the severity of the deficits in the adaptive behaviour (measured by the Intelligence Quotient – IQ). People with IDs are on an increased risk of health-related problems and their health needs are often unrecognized or unmet.

Published by Springer Nature Switzerland AG 2020
I. O. Pappas et al. (Eds.): I3E 2019 Workshops, IFIP AICT 573, pp. 31–41, 2020.
https://doi.org/10.1007/978-3-030-39634-3_4

Utfordringer (PA-ID)

Utfordring

Rekruttering

Utfordring

Samtykke

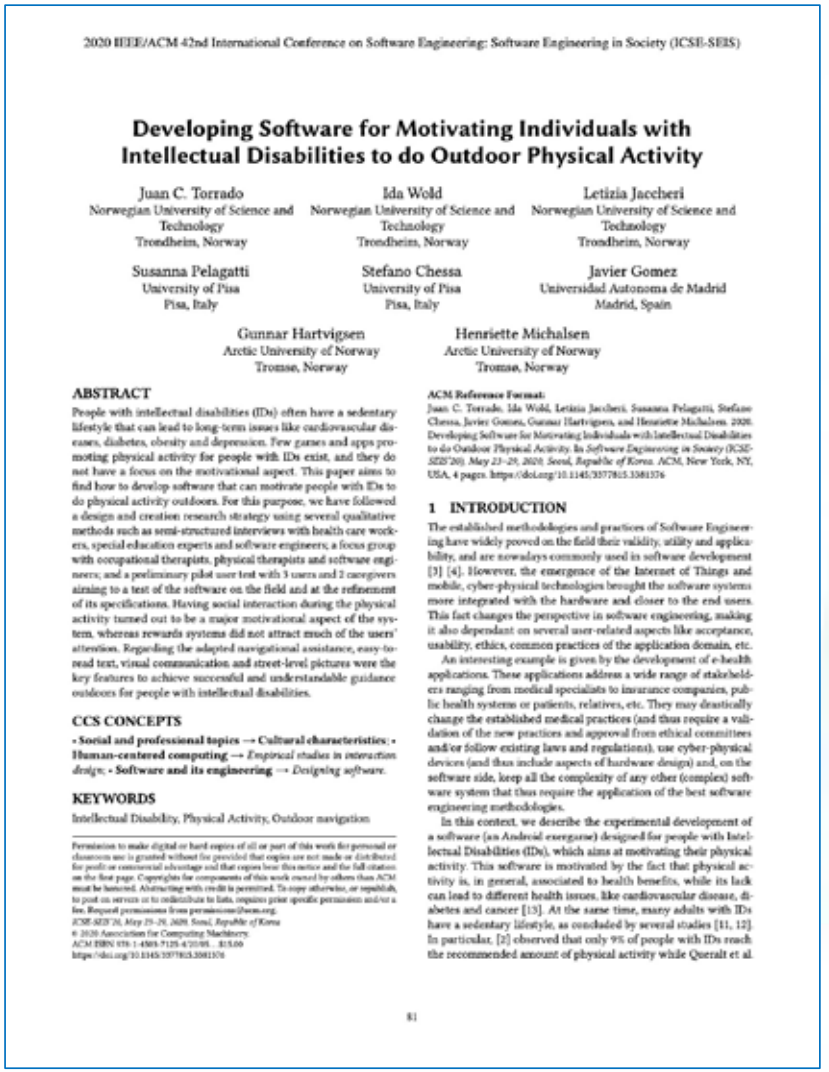
Utfordring

Software engineering

Modellering
Design/Utforming
Testing

Abstract: People with intellectual disabilities (IDs) often have a sedentary lifestyle that can lead to long-term issues like cardiovascular diseases, diabetes, obesity and depression. Few games and apps promoting physical activity for people with IDs exist, and they do not have a focus on the motivational aspect. This paper aims to find how to develop software that can motivate people with IDs to do physical activity outdoors. For this purpose, we have followed a design and creation research strategy using several qualitative methods such as semi-structured interviews with health care workers, special education experts and software engineers; a focus group with occupational therapists, physical therapists and software engineers; and a preliminary pilot user test with 3 users and 2 caregivers aiming to a test of the software on the field and at the refinement of its specifications. Having social interaction during the physical activity turned out to be a major motivational aspect of the system, whereas rewards systems did not attract much of the users' attention. Regarding the adapted navigational assistance, easy-to-read text, visual communication and street-level pictures were the key features to achieve successful and understandable guidance outdoors for people with intellectual disabilities

Torrado, J.C., Wold, I., Jaccheri, L., Pelagatti, S., Chessa, S., Gomez, J., Hartvigsen, G., Michalsen, H. Developing Software for Motivating Individuals with Intellectual Disabilities to do Outdoor Physical Activity. 2020 IEEE/ACM 42nd International Conference on Software Engineering in Society (ICSE-SEIS 2020), (Virtual conference due to the pandemic, June 27 – July 19, 2020). pp. 81-84. Publisher: ACM (ISBN 978-1-4503-7125-4/20/05) (https://doi.org/10.1145/3377815.3381376)



2020 IEEE/ACM 42nd International Conference on Software Engineering: Software Engineering in Society (ICSE-SEIS)

Developing Software for Motivating Individuals with Intellectual Disabilities to do Outdoor Physical Activity

Juan C. Torrado
Norwegian University of Science and Technology
Trondheim, Norway

Ida Wold
Norwegian University of Science and Technology
Trondheim, Norway

Letizia Jaccheri
Norwegian University of Science and Technology
Trondheim, Norway

Susanna Pelagatti
University of Pisa
Pisa, Italy

Stefano Chessa
University of Pisa
Pisa, Italy

Javier Gomez
Universidad Autonoma de Madrid
Madrid, Spain

Gunnar Hartvigsen
Arctic University of Norway
Tromso, Norway

Henriette Michalsen
Arctic University of Norway
Tromso, Norway

ABSTRACT

People with intellectual disabilities (IDs) often have a sedentary lifestyle that can lead to long-term issues like cardiovascular diseases, diabetes, obesity and depression. Few games and apps promoting physical activity for people with IDs exist, and they do not have a focus on the motivational aspect. This paper aims to find how to develop software that can motivate people with IDs to do physical activity outdoors. For this purpose, we have followed a design and creation research strategy using several qualitative methods such as semi-structured interviews with health care workers, special education experts and software engineers; a focus group with occupational therapists, physical therapists and software engineers; and a preliminary pilot user test with 3 users and 2 caregivers aiming to a test of the software on the field and at the refinement of its specifications. Having social interaction during the physical activity turned out to be a major motivational aspect of the system, whereas rewards systems did not attract much of the users' attention. Regarding the adapted navigational assistance, easy-to-read text, visual communication and street-level pictures were the key features to achieve successful and understandable guidance outdoors for people with intellectual disabilities.

CCS CONCEPTS

• **Social and professional topics** → **Cultural characteristics**; • **Human-centered computing** → *Empirical studies in interaction design*; • **Software and its engineering** → *Designing software*.

KEYWORDS

Intellectual Disability, Physical Activity, Outdoor navigation

ICSE-SEIS'20, May 23–29, 2020, Seoul, Republic of Korea

ACM ISBN 978-1-4503-7125-4/20/05…$15.00
https://doi.org/10.1145/3377815.3381376

ACM Reference Format:
Juan C. Torrado, Ida Wold, Letizia Jaccheri, Susanna Pelagatti, Stefano Chessa, Javier Gomez, Gunnar Hartvigsen, and Henriette Michalsen. 2020. Developing Software for Motivating Individuals with Intellectual Disabilities to do Outdoor Physical Activity. In *Software Engineering in Society (ICSE-SEIS'20), May 23–29, 2020, Seoul, Republic of Korea.* ACM, New York, NY, USA, 4 pages. https://doi.org/10.1145/3377815.3381376

1 INTRODUCTION

The established methodologies and practices of Software Engineering have widely proved on the field their validity, utility and applicability, and are nowadays commonly used in software development [3] [4]. However, the emergence of the Internet of Things and mobile, cyber-physical technologies brought the software systems more integrated with the hardware and closer to the end users. This fact changes the perspective in software engineering, making it also dependant on several user-related aspects like acceptance, usability, ethics, common practices of the application domain, etc.

An interesting example is given by the development of e-health applications. These applications address a wide range of stakeholders ranging from medical specialists to insurance companies, public health systems or patients, relatives, etc. They may drastically change the established medical practices (and thus require a validation of the new practices and approval from ethical committees and/or follow existing laws and regulations), use cyber-physical devices (and thus include aspects of hardware design) and, on the software side, keep all the complexity of any other (complex) software system that thus require the application of the best software engineering methodologies.

In this context, we describe the experimental development of a software (an Android exergame) designed for people with Intellectual Disabilities (IDs), which aims at motivating their physical activity. This software is motivated by the fact that physical activity is, in general, associated to health benefits, while its lack can lead to different health issues, like cardiovascular disease, diabetes and cancer [13]. At the same time, many adults with IDs have a sedentary lifestyle, as concluded by several studies [11, 12]. In particular, [2] observed that only 9% of people with IDs reach the recommended amount of physical activity while Queralt et al.


Case:
AI


The EU Framework Programme
for Research and Innovation
HORIZON 2020

I WARIFA-prosjektet utvikles en prototype av et kombinert tidlig risikovurderingsverktøy som vil gi brukerene personlige anbefalinger for behandling av kroniske tilstander - som kreft, kardiovaskulære sykdommer, diabetes og kroniske luftveissykdommer - som representerer de viktigste dødsårsakene for innbyggerne i EU.

WARIFA vil være tilgjengelig for individuelle borgere via et brukervennlig grensesnitt på smarttelefonen.

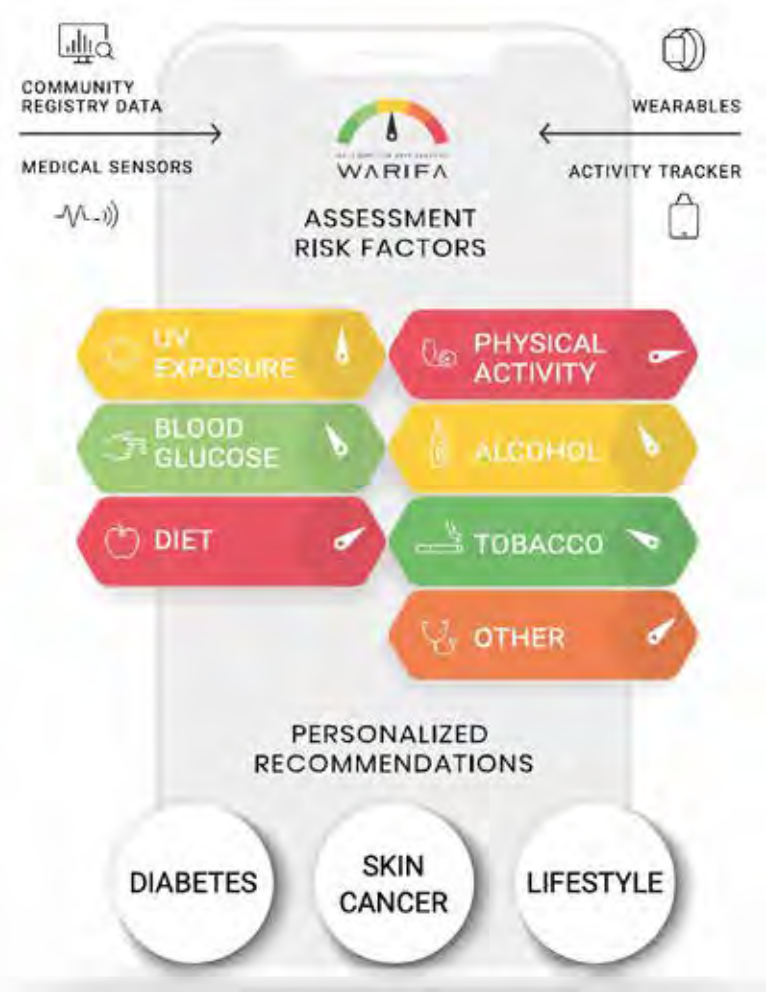
WARIFA

Takket være dette risikovurderingsverktøyet basert på automatisk behandling av både brukergenererte og store data lagret i et sentralt system, vil innbyggerne bli informert om risikoen for å utvikle en bestemt sykdom som de tidligere kanskje ikke var klar over, eller om en kjent sykdom som blir verre.

WARIFA

En spesiell egenskap ved WARIFA-verktøyet vil være muligheten til å gi råd til borgere som er i fare for å få flere sykdommer samtidig.

Anbefalinger som omhandler de ulike sykdommene vil bli slått sammen og balansert for å unngå motstridende råd.



Etiske problemstillinger

- Kliniske studier i flere land
- «Black-box» (GDPR)
- Samtykke til hva?
- Forutsigbarhet når AI-systemet oppdaterer seg undervise
- Hvor blir data lagret?
- For generative AI systemer:
  - Blir våre data gjenstand for videre læring?
  - Er den responsen vi får korrekt eller «oppdiktet»?

Large amount of Internet text data for model training

Human-like text writing

Bias	Privacy and Security	Transparency	Abuse	Authorship
• Data bias, e.g. over-represent younger users • Model bias • Nonrepresentative data labellers •	• Individuals' interaction histories • Lack of fact-checking •	• What training and testing data are used • What model is used •	• Spread misinformation • Impersonate individuals •	• Academic report writing • Creative work generation • Plagiarism • ... ...

FIGURE 1. Examples of ethical concerns on ChatGPT

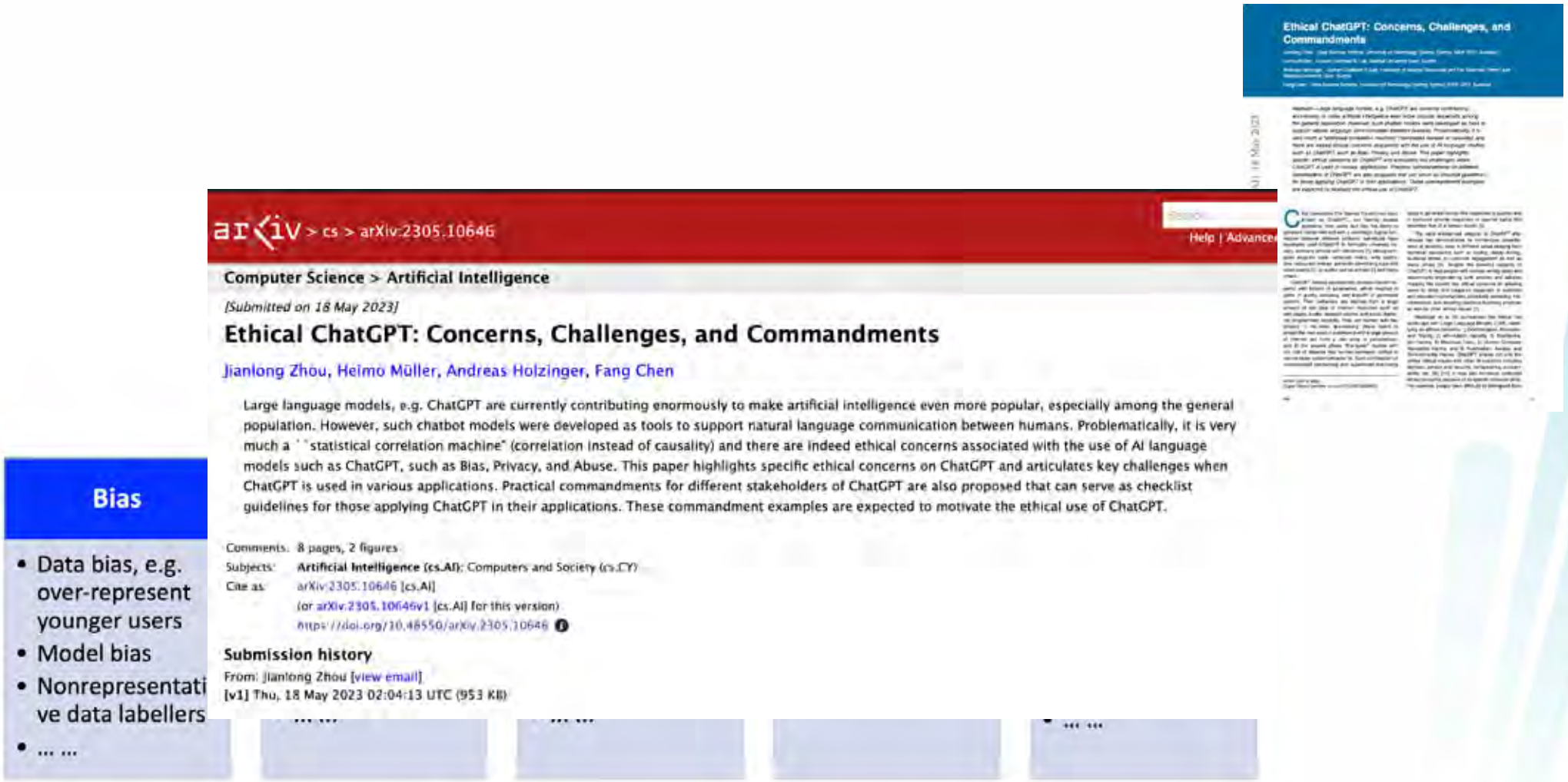
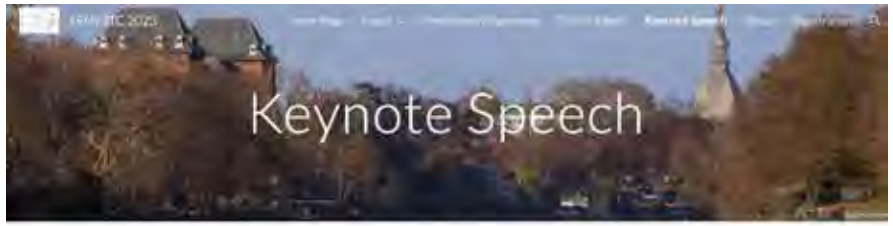


FIGURE 1. Examples of ethical concerns on ChatGPT

Hvor skal vi?


UiT Norges arktiske universitet
FOR DELTAKERE
FOR FORSKERE
OM TROMSØUNDERSØKELSEN
NYHETER
KONTAKT
ENGLISH
Tromsøundersøkelsen
Tromsø-undersøkelsen
Foto: Yngve Olsen Sæbbe / www.nordnorge.com



Gunnar Hartvigsen

Health Informatics and Technology Group
Department of Computer Science
Faculty of Science and Technology
University of Tromsø – The Arctic University of Norway

How home health monitoring, smart sensors, small data and digital dust can save your life

Abstract

To meet the growing demand of health services, we need to think smart about health prevention to avoid obvious risk factors. Efforts must be made to promote early diagnosis. Through continuous use of various medical sensors, health changes can be detected before this result in hospitalization, emergency admissions or even death. But we should not stop with medical sensors. We all leave traces behind when we are using, or being observed by, all kinds of digital equipment. Every online action generates small data and digital dust, which might tell something about our health when the data is analyzed. Every device connected to the network represents a potential health sensor. Together, all these devices can be used to track behavioral changes that may be a consequence of changes in health. The most comprehensive recording of behavior is still done by people's smartphones and smartwatches. These have several sensors built in that together provide a wealth of opportunities to detect even small changes in behavior.

I will in this keynote speech present the research and development in home health monitoring, smart sensors, small data, and digital dust and discuss how this can save your life.

STC 2023 EFMI

EFMI 45 EUROPEAN FEDERATION MEDICAL INFORMATICS

Torino, Italy

25-27 October 2023

How home health monitoring, smart sensors, small data and digital dust can save your life

Small data + big data

Small data + big data

Alle typer data


Polar Vantage and Oura Physical Activity and Sleep Trackers: Validation and Comparison Study


Expectations of users and non-users of wearable sensors and mobile health applications


Using Cloud-Based Physical Activity Data from Google Fit and Apple HealthKit to Expand Recording of Physical Activity Data in a Population Study


Toward a Conversational Agent to Support the Self-Management of Adults and Young Adults With Sickle Cell Disease: Usability and Usefulness Study


BMC Public Health

Succeeding with prolonged usage of consumer-based activity trackers in clinical studies: a mixed methods approach

gunnar.hartvigsen@uit.no